

Appendices and References



LIVERPOOL

Care Pathway

Promoting best practice for care of the dying

ADD OWN ORGANISATIONAL LOGO HERE

Name: Unit no: DOB:

Care Of The Dying Pathway (lcp) (Hospital)

References:

Working Party on Clinical Guidelines In Palliative Care (1997) Changing Gear – Guidelines for Managing the Last Days of Life in Adults. National Council for Hospice and Specialist Palliative Care Services, London (revised and reprinted January 2005)

Ellershaw JE, Wilkinson S (2003) Care of the dying: A pathway to excellence. Oxford: Oxford University Press.

Instructions for use

1. All goals are in **heavy** typeface. Interventions, which act as prompts to support the goals, are in normal type.
2. The palliative care guidelines are printed on the pages at the end of the pathway. Please make reference as necessary.
3. If you have any problems regarding the pathway contact the Palliative Care Team.

Practitioners are free to exercise their own professional judgement; however, any alteration to the practice identified within this LCP must be noted as a variance on the sheet at the back of the pathway.

Criteria for use of the LCP

All possible reversible causes for current condition have been considered:

The multiprofessional team has agreed that the patient is dying, and two of the following may apply: -

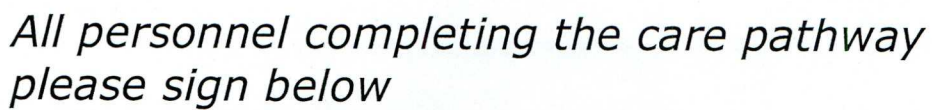
The patient is bedbound ☐

Semi-comatose ☐

Only able to take sips of fluids ☐

No longer able to take tablets ☐

Consultant: Named nurse: Ward:

LCP Nov 2005-version 11



Name: Unit no: Date/Time commenced:

Section 1 Initial assessment	
Diagnosis & Demographics	PRIMARY DIAGNOSIS: SECONDARY DIAGNOSIS:
	Date of In-patient admission: Ethnicity:
	DOB: NHS no: Female <input type="checkbox"/> Male <input type="checkbox"/>
Physical condition	Unable to swallow Yes <input type="checkbox"/> No <input type="checkbox"/> Aware Yes <input type="checkbox"/> No <input type="checkbox"/>
	Nausea Yes <input type="checkbox"/> No <input type="checkbox"/> Conscious Yes <input type="checkbox"/> No <input type="checkbox"/>
	Vomiting Yes <input type="checkbox"/> No <input type="checkbox"/> UTI problems Yes <input type="checkbox"/> No <input type="checkbox"/>
	Constipated Yes <input type="checkbox"/> No <input type="checkbox"/> Catheterised Yes <input type="checkbox"/> No <input type="checkbox"/>
	Confused Yes <input type="checkbox"/> No <input type="checkbox"/> Respiratory tract secretions Yes <input type="checkbox"/> No <input type="checkbox"/>
	Agitation Yes <input type="checkbox"/> No <input type="checkbox"/> Dyspnoea Yes <input type="checkbox"/> No <input type="checkbox"/>
	Restless Yes <input type="checkbox"/> No <input type="checkbox"/> Pain Yes <input type="checkbox"/> No <input type="checkbox"/>
	Distressed Yes <input type="checkbox"/> No <input type="checkbox"/> Other (e.g. oedema, itch) Yes <input type="checkbox"/> No <input type="checkbox"/>
	Comfort measures
Goal 2: PRN subcutaneous medication written up for list below as per protocol (See sheets at back of LCP for guidance)	
Pain Analgesia Yes <input type="checkbox"/> No <input type="checkbox"/>	
Agitation Sedative Yes <input type="checkbox"/> No <input type="checkbox"/>	
Respiratory tract secretions Anticholinergic Yes <input type="checkbox"/> No <input type="checkbox"/>	
Nausea & vomiting Anti-emetic Yes <input type="checkbox"/> No <input type="checkbox"/>	
Dyspnoea Anxiolytic / Muscle relaxant Yes <input type="checkbox"/> No <input type="checkbox"/>	
Goal 3: Discontinue inappropriate interventions	
Blood test (including BM monitoring) Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	
Antibiotics Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	
I.V.'s (fluids/medications) Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	
Not for cardiopulmonary resuscitation recorded Yes <input type="checkbox"/> No <input type="checkbox"/>	
(Please record below & complete appropriate associated documentation - policy/procedure)	
Deactivate cardiac defibrillators (ICD's) Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	
Contact patient's Cardiologist	
Refer to local policy and procedures	
Information leaflet given to patient / carer if appropriate	
Doctor's signature: Date:	
Goal 3a: Decisions to discontinue inappropriate nursing interventions taken Yes <input type="checkbox"/> No <input type="checkbox"/>	
Routine turning regime – reposition for comfort only – consider pressure relieving mattress – & appropriate assessments re skin integrity - taking vital signs. If BM monitoring in place reduce frequency as appropriate e.g. once daily	
Goal 3b: Syringe driver set up within 4 hours of doctors order Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	
Nurse signature: Date: Time:	

4



Name: Unit no: Date:

Codes (please enter in columns) A= Achieved V=Variance (not a signature)							
Section 2	Patient problem/focus	04:00	08:00	12:00	16:00	20:00	24:00
Ongoing assessment Pain Goal: Patient is pain free <ul style="list-style-type: none">• Verbalised by patient if conscious• Pain free on movement• Appears peaceful• Consider need for positional change							
Agitation Goal: Patient is not agitated <ul style="list-style-type: none">• Patient does not display signs of delirium, terminal anguish, restlessness (thrashing, plucking, twitching)• Exclude retention of urine as cause• Consider need for positional change							
Respiratory tract secretions Goal: Excessive secretions are not a problem <ul style="list-style-type: none">• Medication to be given as soon as symptoms arise• Consider need for positional change• Symptom discussed with family/other							
Nausea & vomiting Goal: Patient does not feel nauseous or vomits <ul style="list-style-type: none">• Patient verbalises if conscious							
Dyspnoea Goal: Breathlessness is not distressing for patient <ul style="list-style-type: none">• Patient verbalises if conscious.• Consider need for positional change.							
Other symptoms (e.g. oedema, itch)							
Treatment/procedures Mouth care Goal: Mouth is moist and clean <ul style="list-style-type: none">• See mouth care policy• Mouth care assessment at least 4 hourly• Frequency of mouth care depends on individual need• Family/other involved in care given							
Micturition difficulties Goal: Patient is comfortable <ul style="list-style-type: none">• Urinary catheter if in retention• Urinary catheter or pads, if general weakness creates incontinence							
Medication (If medication not required please record as N/A) Goal: All medication is given safely & accurately <ul style="list-style-type: none">• If syringe driver in progress check at least 4 hourly according to monitoring sheet							
Signature							
Repeat this page 24 hrly. Spare copies on Ward If you have charted "V" against any goal so far, please complete variance sheet on the back page							



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Nausea & vomiting Goal: Patient does not feel nauseous or vomits <ul style="list-style-type: none"> Patient verbalises if conscious 							
Dyspnoea Goal: Breathlessness is not distressing for patient <ul style="list-style-type: none"> Patient verbalises if conscious. Consider need for positional change. 							
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Signature							
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Name: Unit no: Date:

Codes (please enter in columns) A= Achieved V=Variance		08:00	20:00
Mobility/Pressure area care	Goal: Patient is comfortable and in a safe environment <ul style="list-style-type: none">Clinical assessment of:<ul style="list-style-type: none">Skin integrityNeed for positional changeNeed for special mattressPersonal hygiene, bed bath, eye care needs		
Bowel care	Goal: Patient is not agitated or distressed due to constipation or diarrhoea		
Psychological/Insight support	Patient Goal: Patient becomes aware of the situation as appropriate <ul style="list-style-type: none">Patient is informed of proceduresTouch, verbal communication is continued		
	Family/other Goal: Family/other are prepared for the patient's imminent death with the aim of achieving peace of mind and acceptance <ul style="list-style-type: none">Check understanding of nominated family/others / younger adults / childrenCheck understanding of other family/others not present at initial assessmentEnsure recognition that patient is dying & of the measures taken to maintain comfortChaplaincy Team support offered		
Religious/Spiritual support	Goal: Appropriate religious/spiritual support has been given <ul style="list-style-type: none">Patient/other may be anxious for self/othersSupport of Chaplaincy Team may be helpfulConsider cultural needs		
Care of the family/others	Goal: The needs of those attending the patient are accommodated <ul style="list-style-type: none">Consider health needs & social support.Ensure awareness of ward facilities		
Signature			
Health Professional Signature Early:..... Late: Night:.....			
Multidisciplinary progress notes			



Name: Unit no: Date:

Codes (please enter in columns) A= Achieved V=Variance (not a signature)							
Section 2	Patient problem/focus	04:00	08:00	12:00	16:00	20:00	24:00
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Nausea & vomiting Goal: Patient does not feel nauseous or vomits <ul style="list-style-type: none">• Patient verbalises if conscious							
Dyspnoea Goal: Breathlessness is not distressing for patient <ul style="list-style-type: none">• Patient verbalises if conscious.• Consider need for positional change.							
Other symptoms (e.g. oedema, itch)							
Treatment/procedures Mouth care Goal: Mouth is moist and clean <ul style="list-style-type: none">• See mouth care policy• Mouth care assessment at least 4 hourly• Frequency of mouth care depends on individual need• Family/other involved in care given							
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Signature							

Repeat this page 24 hrly. Spare copies on Ward
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Bowel care	Goal: Patient is not agitated or distressed due to constipation or diarrhoea		
Psychological/Insight support	Patient Goal: Patient becomes aware of the situation as appropriate <ul style="list-style-type: none">• Patient is informed of procedures• Touch, verbal communication is continued		
	Family/other Goal: Family/other are prepared for the patient's imminent death with the aim of achieving peace of mind and acceptance <ul style="list-style-type: none">• Check understanding of nominated family/others / younger adults / children• Check understanding of other family/others not present at initial assessment• Ensure recognition that patient is dying & of the measures taken to maintain comfort• Chaplaincy Team support offered		
Religious/Spiritual support	Goal: Appropriate religious/spiritual support has been given <ul style="list-style-type: none">• Patient/other may be anxious for self/others• Support of Chaplaincy Team may be helpful• Consider cultural needs		
Care of the family/others	Goal: The needs of those attending the patient are accommodated <ul style="list-style-type: none">• Consider health needs & social support.Ensure awareness of ward facilities		
Signature			
Health Professional Signature Early:..... Late: Night:.....			
Multidisciplinary progress notes			



Name: Unit no: Date:

SECTION 3 Verification of death

Date of death: Time of death:

Persons present:

Notes:

Signature: Time verified:

Care after death	Goal 12: GP Practice contacted re patient's death Date ____/____/____ Yes <input type="checkbox"/> No <input type="checkbox"/> <ul style="list-style-type: none">• If out of hours contact on next working day• Message can be left with receptionist	
	Goal 13: Procedures for laying out followed according to hospital policy Yes <input type="checkbox"/> No <input type="checkbox"/> <ul style="list-style-type: none">• Carry out specific religious / spiritual / cultural needs - requests	
	Goal 14: Procedure following death discussed or carried out Yes <input type="checkbox"/> No <input type="checkbox"/> Check for the following: <ul style="list-style-type: none">• Explain mortuary viewing as appropriate• Family aware cardiac devices (ICD's) or pacemaker must be removed prior to cremation• Post mortem discussed as appropriate.• Input patients death on hospital computer	
	Goal 15: Family/other given information on hospital procedures Yes <input type="checkbox"/> No <input type="checkbox"/> <ul style="list-style-type: none">• Hospital information booklet given to family/other about necessary legal tasks• Relatives/other informed to ring Bereavement Office after 10.00am on next working day to make an appointment to collect death certificate	
	Goal 16: Hospital policy followed for patient's valuables & belongings Yes <input type="checkbox"/> No <input type="checkbox"/> <ul style="list-style-type: none">• Belongings and valuables are signed for by identified person• Property packed for collection.• Valuables listed and stored safely	
	Goal 17: Necessary documentation & advice is given to the appropriate person Yes <input type="checkbox"/> No <input type="checkbox"/> <ul style="list-style-type: none">• 'What to do after death' booklet given (DHSS)	
	Goal 18: Bereavement leaflet given Yes <input type="checkbox"/> No <input type="checkbox"/> <ul style="list-style-type: none">• Information leaflet on grieving and local support given	
	If you have charted "No" against any goal so far, please complete variance sheet at the back of the pathway before signing below	
	Health Professional signature: Date:	
Have you completed the last 4 & 12 hourly observation Please contact the Palliative Care Team to inform them that this patient was on a pathway.		



Name: Unit no: NHS no:

Variance analysis

What Variance occurred & why?	Action Taken	Outcome
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....



Name: Unit no: NHS no:

Variance analysis

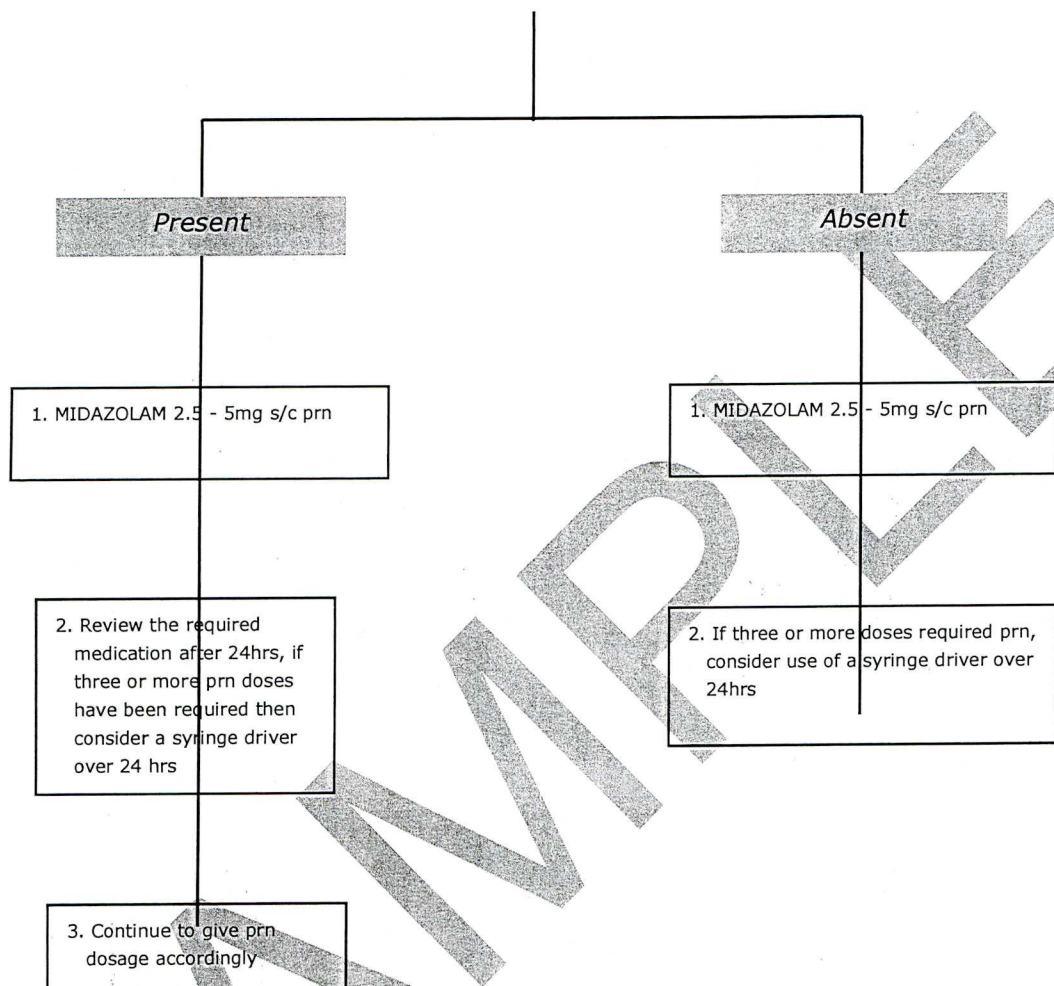
What Variance occurred & why?	Action Taken	Outcome
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....
Signature..... Date/Time.....	Signature..... Date/Time.....	Signature..... Date/Time.....



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Terminal restlessness and agitation

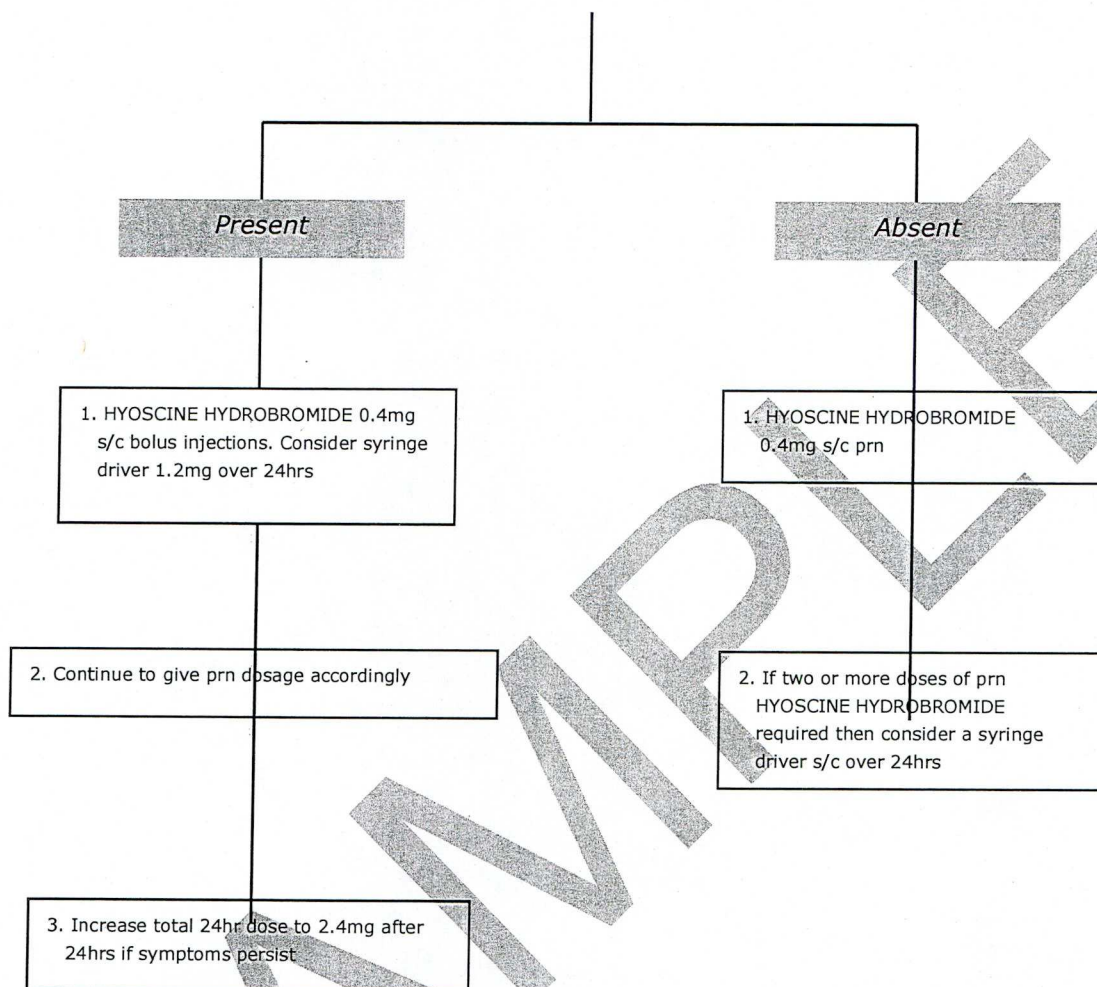


SUPPORTIVE INFORMATION:

- If symptoms persist contact the Palliative Care Team
- Anticipatory prescribing in this manner will ensure that in the last hours / days of life there is no delay responding to a symptom if it occurs.
- *These guidelines are produced according to local policy & procedure & you may want to alter them for local use and reference them accordingly*



Respiratory tract secretions

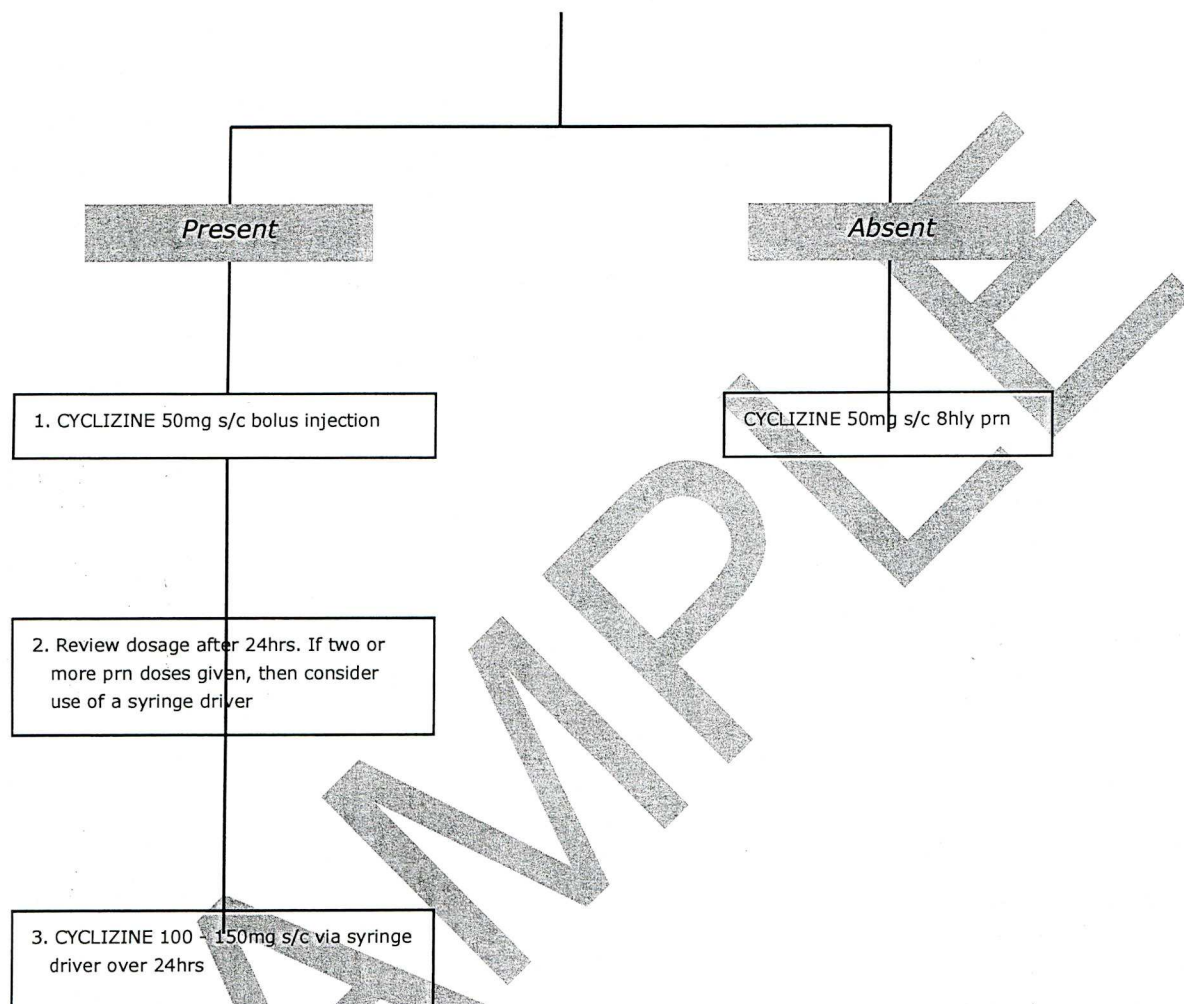


SUPPORTIVE INFORMATION:

- If symptoms persist contact the Palliative Care Team
- Glycopyrronium 0.4mg s/c prn may be used as an alternative
- Anticipatory prescribing in this manner will ensure that in the last hours / days of life there is no delay responding to a symptom if it occurs.
- *These guidelines are produced according to local policy & procedure & you may want to alter them for local use and reference them accordingly*



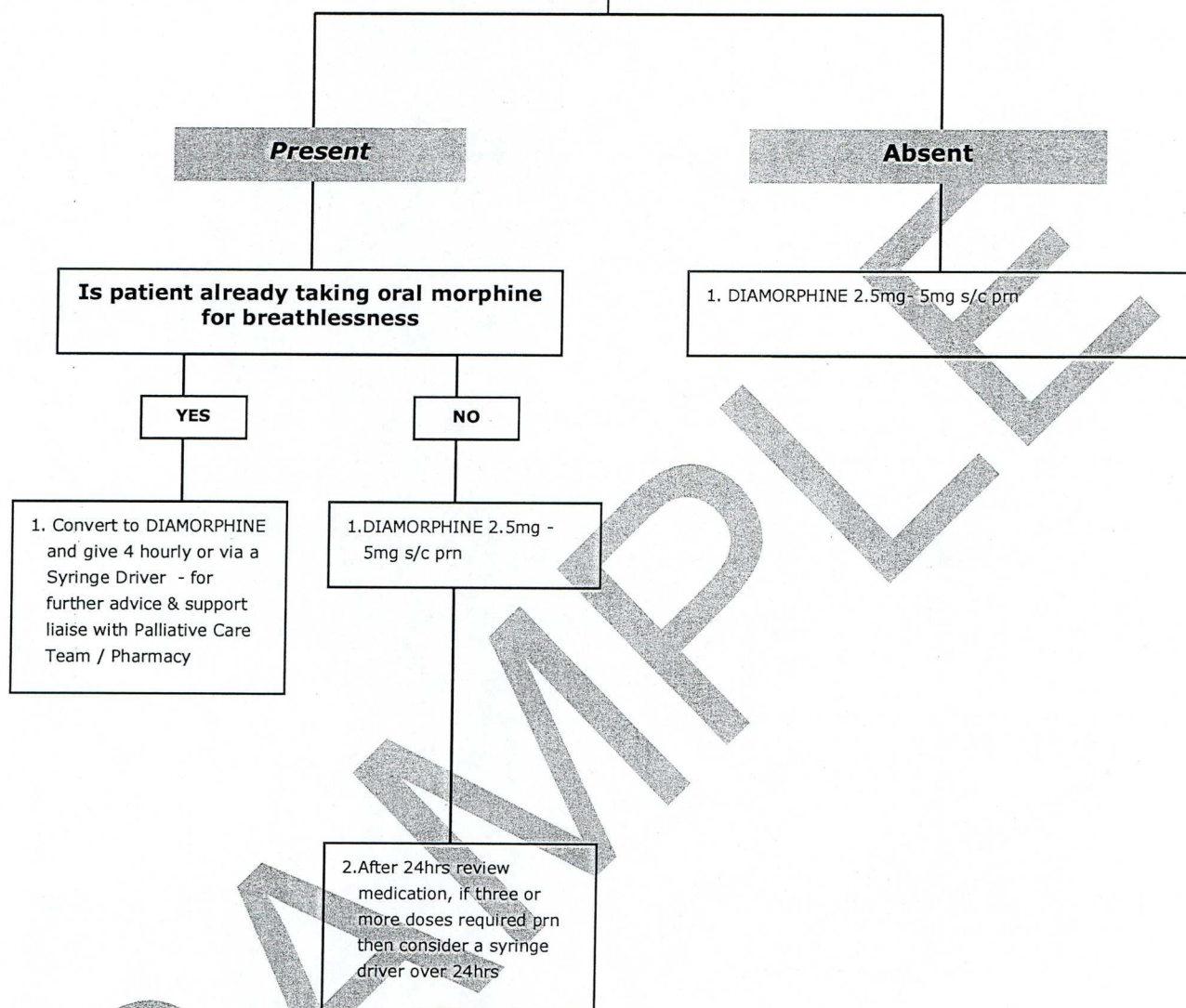
Nausea and vomiting



SUPPORTIVE INFORMATION:

- N.B. Always use water for injection when making up Cyclizine.
- If symptoms persist contact the Palliative Care Team.
- Cyclizine is not recommended in patients with heart failure.
Alternative antiemetics according to local policy & procedure may be prescribed
e.g. **Haloperidol s/c 2.5 – 5mg prn (5 – 10mg via a s/c syringe Driver over 24 hrs)**
Levomepromazine s/c 6.25mg prn (6.25 – 12.5 mg via a s/c syringe Driver over 24hrs)
- Anticipatory prescribing in this manner will ensure that in the last hours / days of life there is no delay responding to a symptom if it occurs.
- *These guidelines are produced according to local policy & procedure & you may want to alter them for local use – many areas have complex algorithms as guidance for the management of nausea or vomiting, and may be referenced accordingly*

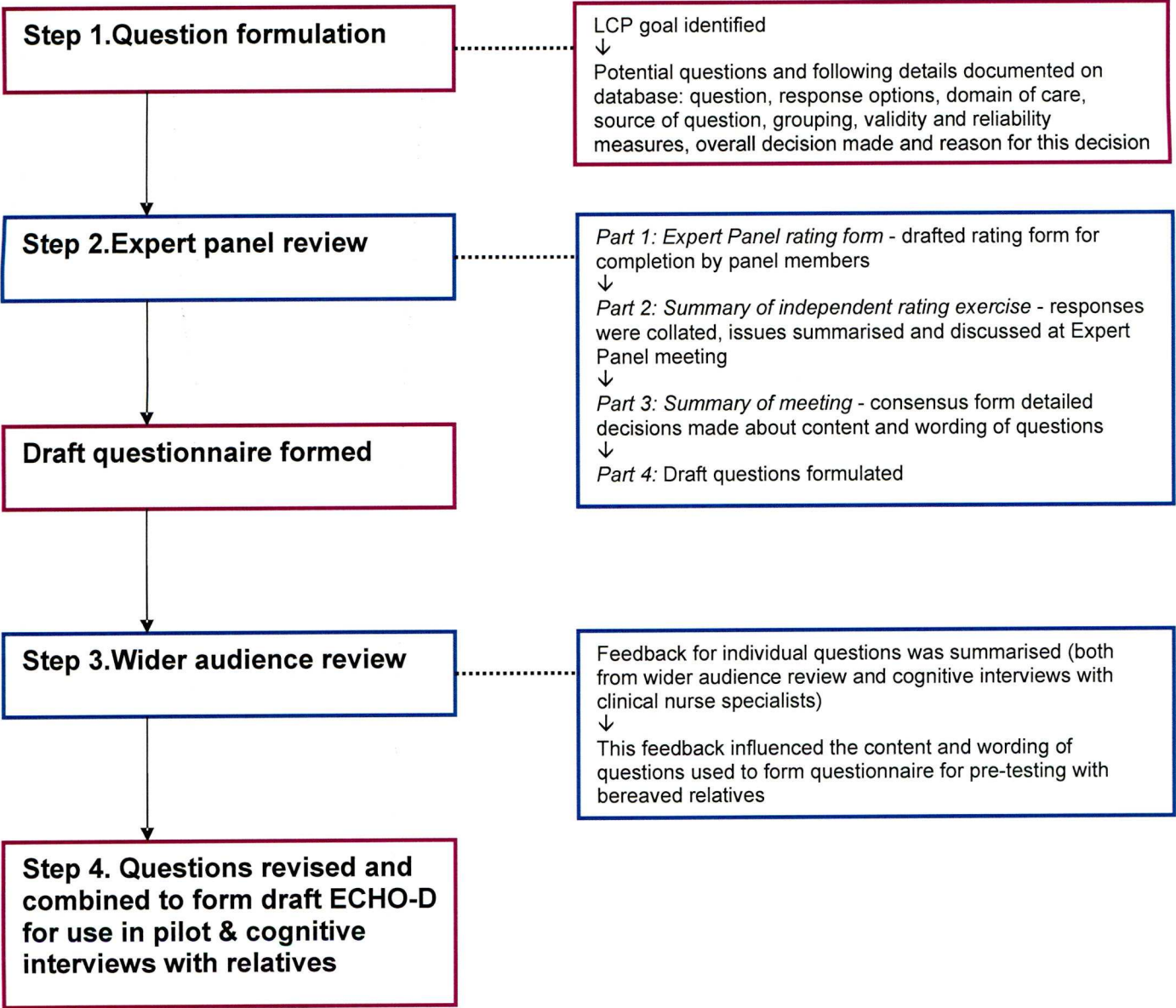
Dyspnoea



SUPPORTIVE INFORMATION:

- If the patient is breathless and anxious consider Midazolam stat 2.5mg s/c prn
- If symptoms persist contact the Palliative Care Team.
- Anticipatory prescribing in this manner will ensure that in the last hours / days of life there is no delay responding to a symptom if it occurs.
- *These guidelines are produced according to local policy & procedure & you may want to alter them for local use and reference accordingly*

Appendix 2. Summary of process for questionnaire development



Example of the process used to develop questionnaire (discontinuing inappropriate interventions)

Step 1: Question formulation

LCP goal 3: Discontinue inappropriate interventions

Question Number	Question	Response categories	Domain	Source of question	Grouping
1	How would you rate this aspect of (patient's name) dying experience? Avoid being in dialysis or mechanical ventilation	0-10 response scale: terrible experience to almost perfect experience	Physical	QODD	Generic
2	During the last day of life, did (PATIENT) have a resuscitation effort? (that is, was CPR done when (his/her) heart stopped)	Yes/No/Don't know	Physical	TIME	Generic
3	During the last day of life, did (PATIENT) attached to a respirator or ventilator? (that is, a machine which helps breathing)	Yes/No	Physical	TIME	Generic
4	During the last day of life, was (PATIENT) fed through a tube?	Yes/No	Physical	TIME	Generic
5	During the last day of life, did (PATIENT) receive dialysis (or, artificial kidney treatments)?	Yes/No	Physical	TIME	Generic
6	On your ward, do patients who are dying have a 'do not attempt resuscitation' order written in their case notes?	Yes, always/usually/very rarely/never	Physical	MCPCIL	HCT
7	On your ward, do patients who are dying have intravenous or subcutaneous fluids until the point of death?	Yes, always/usually/very rarely/never	Physical	MCPCIL	HCT
8	Do you feel that patients who are dying should have intravenous or subcutaneous fluids up to the point of death?	Yes, always/usually/very rarely/never	Physical	MCPCIL	HCT
9	During the last two days, did you feel s/he had any unnecessary medical interventions? (for example excessive blood tests)	Yes/No	Physical	CM	Generic

LCP goal 3: Discontinue inappropriate interventions

Question Number	Validity	Reliability	Decision – accept or reject question	Reasons if rejected / requires modifications
1	Measurement/Construct/Face/Content	Internal consistency	Reject	Too medicalised
2	Face/Construct/Criterion	Internal consistency	Reject	Not applicable for LCP
3	Face/Construct/Criterion	Internal consistency	Reject	Too medicalised; not as relevant for this questionnaire
4	Face/Construct/Criterion	Internal consistency	Reject	Too medicalised; not as relevant for this questionnaire
5	Face/Construct/Criterion	Internal consistency	Reject	Too medicalised; not as relevant for this questionnaire
6	None	None	Reject	Focus for HCT
7	None	None	Reject	Focus for HCT
8	None	None	Modify & accept for EP review	Change terminology to be relevant for relatives
9	None	None	Accept for EP review	Ask about whether had fluids through a 'drip' and whether it was important

Step 2: Expert Panel review

Part 1: Expert panel rating form

LCP Goal 3: Discontinue inappropriate interventions.

With reference to the above LCP goal, please comment on the following questions / statements in the table below.

Question / Statement	Category	Clarity	Knowledge / memory	Sensitivity	Response categories	Comments
1. During these last two days, did you feel s/he had any unnecessary medical interventions (for example excessive blood tests)? Yes / No						
2. During these last two days, did s/he have fluids given through a 'drip'? Yes / No						
3. If yes: Did you feel it was important for him/her to have fluids through a 'drip' up until the moment that s/he died? Yes / No						

Do you feel other questions should be asked about these goals? (If so, please state below)

.....

.....

.....

Step 2: Expert Panel review

Part 2: Summary of Expert Panel independent rating exercise

Expert panel review table – Section 1 of LCP

Question / Statement	Tally	Comments	Revised question	Points for discussion at face-to-face meeting
<u>Goal 3. (a)</u> During these last two days, did you feel s/he had any unnecessary medical interventions (for example excessive blood tests)? Yes / No	A – 5 B – 1 C – 0	Add in 'don't know' option	During these last two days, did you feel s/he had any unnecessary medical interventions (for example excessive blood tests)? Yes / No / <u>Don't know</u>	Check consensus
<u>Goal 3. (b)</u> During these last two days, did s/he have fluids given through a 'drip'? Yes / No	A – 4 B – 2 C – 0	Add in 'don't know' option	During these last two days, did s/he have fluids given through a 'drip'? Yes / No / <u>Don't know</u>	Check consensus
<u>Goal 3. (c)</u> Did you feel it was important for him/her to have fluids through a 'drip' up until the moment that s/he died? Yes / No	A – 3 B – 2 C – 1	Tricky question – if patient didn't, will it suggest to relative that they should have Add in 'don't know'	To be discussed <u>If s/he was given fluids through a 'drip', on balance do you feel this was best for him /her?</u> <u>Yes / No / Don't know / S/he did not have fluids given through a 'drip'?</u>	Should this question be kept? Additional questions? Were reasons given for why it was stopped; did relatives agree with this; food and nourishment?
<u>Goal 3.</u> Additional questions	N/A	CPR discussion	N/A	Is a question required regarding CPR decisions?

Step 2: Expert Panel review

Part 2: Summary of Expert Panel independent rating exercise (notes for face-to-face meeting)

Goal 3: Discontinue inappropriate interventions

Consensus: The panel thought these two questions could be used:

Question 1: During these last two days, did you feel s/he had any unnecessary medical interventions (for example excessive blood tests)?
Yes / No / Don't know

Question 2: During these last two days, did s/he have fluids given through a 'drip'?
Yes / No / Don't know

Issue: Should we keep Question 3 (below)?

Question 3: Did you feel it was important for him/her to have fluids through a 'drip' up until the moment that s/he died?
Yes / No

Issue: Should we ask any additional questions?

For example questions asking whether reasons given regarding why the fluid was stopped / did they want the fluids to continue after they were stopped / relatives' views on food and nourishment

Issue: Should we ask a question regarding CPR?

Step 2: Expert Panel review

Part 3: Summary of Expert Panel face-to-face meeting

Expert panel meeting – consensus form LCP: Section 1

Section 1: initial assessment		Panel consensus			
LCP Goal	Question	Accept question	Discard question	Comments	Change question – qualifying statement(s)
3	(a)	✓			Add 'don't know'
3	(b)	✓			Add 'don't know'
3	(c)	✓		Dependant on 3 (b), what about patients who don't have drip	Add 'not applicable' as additional response option Need further question – what they thought about the decision / whether discussion had
3	Additional questions	State decision and wording of question (if applicable): Resuscitation futile if already had decision to commence LCP; relatives can't decide; already have 'Red card' system; wording must be careful			
		Don't include question for now			

Step 2: Expert Panel review

Part 4: Draft questionnaire formulation

B7. Did any of the doctors and nurses discuss with you the provision of fluids for hydration in the last two days of life?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

B8. How were fluids given to him/her in the last two days of his/her life?

- | | |
|--|--------------------------|
| By moistening his/her mouth with a damp sponge | <input type="checkbox"/> |
| By giving sips of water | <input type="checkbox"/> |
| By giving fluids through a 'drip' | <input type="checkbox"/> |
| No fluids were given | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |
| Other (please specify) _____ | |

B9. In your opinion, was this way of providing fluids, the appropriate one?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

Please feel free to comment if you wish to: _____

B10. In your view, did s/he have any unnecessary tests or checks (for example too many blood tests or blood pressure checks)?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

Step 3: Wider audience review (summary of feedback)

Section	Question	Comments	Action	Feedback from team interviews	Action
B	7	Clarity – ‘need for fluids’ rather than ‘provision of fluids’; ‘ordering of fluid’; unclear; term ‘hydration’	Pre-test – mentioned by 5 people; change wording to ‘whether fluids were required’	Medicalised term	Further change to wording – pre-test with relatives to check understanding
B	8	Clarity – question seems ambiguous; will it raise issues if fluids weren’t given	Pre-test	Didn’t seem to cause confusion – helps clarify previous question	Changed order – pre-test if raises issues
B	9	Clarity – use ‘most appropriate’ rather than ‘the appropriate one’	Don’t change – only 1 person mentioned	Didn’t seem to cause confusion	Look at relatives’ responses
B	10	Clarity – would relatives know this?	Pre-test	Didn’t seem to cause confusion	Pre-test with relatives

Step 4: Wider audience review

Questions for draft questionnaire to be used with bereaved relatives

B7. How were fluids given to him/her in the last two days of his/her life?

- | | |
|--|--------------------------|
| By moistening his/her mouth with a damp sponge | <input type="checkbox"/> |
| By giving sips of water | <input type="checkbox"/> |
| By giving fluids through a 'drip' | <input type="checkbox"/> |
| No fluids were given | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |
| Other (please specify) _____ | |

B8. In your opinion, was this way of providing fluids the appropriate one?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

Please feel free to comment if you wish to: _____

B9. Did any of the doctors or nurses discuss with you whether giving fluids through a 'drip' would be appropriate in the last two days of life?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

B10. In your view, did s/he have any unnecessary tests or checks (for example too many blood tests or blood pressure checks)?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

6 December 2005

Professor J Ellershaw
Professor of Palliative Medicine
Royal Liverpool University Hospital
Prescot Street
Liverpool
L7 8XP

Dear Professor Ellershaw

Full title of study: How well do patients die? The development of a questionnaire assessing relative's perceptions regarding quality of care for dying patients
REC reference number: 05/Q1505/126

Thank you for your letter of 18 November 2005, responding to the Committee's request for further information on the above research.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		03 October 2005
Investigator CV	Professor J E Ellershaw	07 October 2005
Investigator CV	Evelyn M I Williams	07 October 2005
Protocol	1.6	01 October 2005
Statistician Comments		10 September 2005
Questionnaire	3	28 September 2005
Letter of invitation to participant	1.2	30 September 2005
Participant Information Sheet (PIS)	1.3	11 November 2005
Participant Consent Form	1.3	11 November 2005
Pilot Letter of Invitation to participant	1.2	30 September 2005
Interview Structure	1.1	06 October 2005
Reminder Letter	1.3	11 November 2005

Pilot Response Form	1.1	20 September 2005
Response Form	1.1	20 September 2005
Information document from Marie Curie Palliative Care Institute		10 October 2005
GP Letter	1.2	30 September 2005
Consultant Letter	1.2	30 September 2005
Certificate of membership for MDDUS	Professor J E Ellershaw	19 September 2005
Pilot Participant Information Sheet (PIS)	1.4	11 November 2005

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/Q1505/126	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely


Dr T S Purewal
Chair

E-mail: jenny.cross@centralliverpoolpct.nhs.uk

Enclosures Standard approval conditions

Copy to: Dr R Owen, R&D Department, Royal Liverpool University Hospital
 Dr C Mayland, Palliative Care Institute

Appendix 4: Letter of invitation (pilot)

Marie Curie Palliative Care Institute
Palliative Care Team
Royal Liverpool Hospital
Prescot Street
Liverpool L7 8XP
Tel: 0151 706 2274
Date

Dear *Name*

RE: How well do we care for dying patients? Assessing relatives' views regarding the quality of care at end-of-life.

Study by Dr Catriona Mayland, Dr EMI Williams and Professor JE Ellershaw from the Marie Curie Palliative Care Institute, Liverpool

The above project, led by Professor Ellershaw, is looking at the quality of care received by people in their last days of life and the experiences of their family and friends during this time. It is very important to know about the experiences of people at this difficult time. The information will help to plan better end-of-life care in the future.

As part of the project, a questionnaire has been developed for use with relatives. We need to pilot the questionnaire to ensure that questions can be understood and that all the important aspects of care are included.

The Psychological and Social Care Team based at the Marie Curie Hospice, Liverpool identified you as someone who may wish to participate in this project. We would like to invite you to help with this study. If you wish to participate, please complete the response form with your contact details. All information will be treated confidentially. An information sheet about the project is enclosed.

Participation in this project would involve completing a questionnaire. Additionally, we would like some participants to attend a one-to-one interview. This interview would ask about how you found the questionnaire and discuss ways that it could be improved. Finally, you will be asked if you would be willing to complete the questionnaire again approximately four weeks later.

If you do not wish to take part, please return the response form so we do not contact you again.

Thank you for reading this information.

Yours sincerely

Dr Catriona Mayland

Clinical Research Fellow in Palliative Medicine

Appendix 5: PARTICIPANT INFORMATION SHEET

How well do we care for dying patients? Assessing relatives' views about the quality of care at the end-of-life.

Contact for Further Information:

Dr Catriona Mayland, Clinical Research Fellow in Palliative Medicine
Marie Curie Palliative Care Institute, Directorate of Palliative Care, Royal
Liverpool Hospital, Liverpool.
Tel: 0151 706 2274 Email: catriona.mayland@rlbuht.nhs.uk

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

The purpose of this study is to look at the quality of care and support provided to patients in their last days of life, and to their families and friends during this time. As part of this project, we need to see that the questionnaire we wish to use is sensitive, easy to understand and includes all the important aspects of care at the end of life.

Why have I been chosen?

The Psychological and Social Care Team based at the Marie Curie Hospice, Liverpool identified you as someone who may wish to participate in this project. Other people, who were family members or friends to patients who died in Marie Curie Hospice and the Royal Liverpool & Broadgreen University Hospitals, will also be invited to participate in this research (approximately 50 people).

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. Participation is voluntary and you may change your mind or choose not to continue in the study at any time, without having to give a reason for doing so.

What will happen to me if I take part?

1. You will be asked to return the response form giving your contact details. One of the research team will then contact you and arrange to send you a questionnaire, which will take an about an hour to complete. The questionnaire contains a series of questions relating to the care and experiences that your family member or friend received in their last days of life.
2. Within the questionnaire, you will be asked if you are willing to participate in an interview. The interview will ask your opinion about the wording and sensitivity of the questions and whether you feel additional questions should be included. If you would like to participate in an interview, the research team will contact you to arrange a suitable time for this to occur. You will be asked to sign a consent form and with your permission the interview will be tape-recorded. The interviewer will listen to these tape recordings and may use them to form a written account of the interview. Both the tape recordings and the written accounts will be destroyed at the end of the project, estimated to be 2011.
3. Finally, within the questionnaire, you will be asked if you are prepared to complete the same questionnaire again in approximately four weeks time. If you indicate you would be willing to do this, the questionnaire will be sent out again.

What do I have to do?

To take part in this study, you should complete and return the response card. The research team will then contact you to send a questionnaire.

If you indicate that you would be willing to participate in an interview, the research team will contact you to arrange a convenient time for the interview. The interview will be audio taped and depending on your preference could occur at the Royal Liverpool Hospital or the Marie Curie Hospice, Liverpool. If neither of these places is suitable, alternative arrangements can be made. If you indicate that you would be willing to complete the questionnaire again, a further copy will be sent out approximately four weeks after the first one.

However, if you decide not to participate, please return the response form using the SAE provided so that the research team do not contact you again.

What is the procedure that is being tested?

We are looking at see whether the care received by patients dying from cancer varies between the hospice and hospital setting.

What are the possible disadvantages and risks of taking part?

We appreciate this is a sensitive area and it is possible that you may find some of the questions upsetting. If this is the case, you do not need to continue completing the questionnaire and you can stop at any time.

Additional support will be available from the Psychological and Social Care Team based at the Marie Curie Hospice, Liverpool. Christine Sutcliffe, Principal Social Worker can be contacted directly on telephone number 0151 801 1480.

What are the possible benefits of taking part?

There may be no direct benefits for you from taking part in this study. However, some people may find it useful to have the opportunity to give feedback about the care their family member received. On a wider perspective, the benefits of taking part will help highlight the areas of care that need to be improved as regards care of dying patients.

What if something goes wrong?

The Liverpool Ethics Committee has reviewed the study and it is unlikely that you will be harmed in any way. However, in the event that some harm may befall you, there are no special compensation arrangements for this study.

If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal Marie Curie Hospice and National Health Service complaints mechanisms would be available to you.

If you have concerns about any aspect of this study, then please ask.

Will my taking part in this study be kept confidential?

All information that is collected about you and your family member or friend during the course of the research will be kept strictly confidential. The information shall be carefully stored until the completion of the project, estimated to be 2011.

Although we do not have details of your individual General Practitioner and Consultant, all GPs in the Merseyside and Cheshire area, the Medical Director at the Royal Liverpool & Broadgreen University Hospitals and the Consultants at the Marie Curie Hospice, Liverpool are aware of this research project.

What will happen to the results of the research study?

The results from the study will be written up and presented at appropriate professional conferences and a report for the Marie Curie Palliative Care Institute will be published. If you would like to receive a copy of this report, this can be arranged.

Who is organising and funding the research?

The research project has been organised by the Marie Curie Palliative Care Institute. The principle co-investigator is Dr Catriona Mayland and she will take overall responsibility for the security and confidentiality of the information given in the questionnaire. Marie Curie Cancer Care has provided funding for the project.

If you agree to participate in this study you will be given a copy of the information sheet and a signed consent form to keep.

Thank you for taking the time to read this information sheet.

Appendix 6: Response form (pilot)

Please tick all the boxes that apply to you:

1. I wish to participate in this project by

- Completing a postal questionnaire ☐
- Agreeing to be contacted about having a face-to-face interview ☐

My contact details are as follows:

Name: _____

Address: _____

Telephone number: _____

Email (if applicable): _____

2. I do not wish to participate in this project. ☐

If you would like to, please comment on your reasons for not participating.

Please return this response form in the freepost envelope enclosed.
Thank you.

Appendix 7: Draft questionnaire used in pilot

ECHOD

Evaluating Care & Health Outcomes for the Dying

- This is a questionnaire on the care received by people in the last hours and days of life and the experiences of their families and friends during that time.
- The team at the Marie Curie Palliative Care Institute consider the care of dying patients to be a priority. We also think it is important to find out more about the care and support you, your family and friends received at the time of death. Your views are, therefore, important to us. Please fill in as much of the questionnaire as you can.
- We realise this questionnaire may bring back strong memories and emotions and that reading it for the first time may be difficult. You may wish to wait and find someplace quiet to read the questionnaire. If you feel upset or distressed in any way, you do not have to continue with the questionnaire and can stop at any time. However, if you wish to, you can return to the questionnaire at a future time.

**Your answers will, of course, be treated as strictly confidential.
Individuals will not be identifiable in the reports we write.**

- You have been sent this questionnaire as you are registered as the next of kin to a patient who died in the Royal Liverpool & Broadgreen University Hospitals or the Marie Curie Hospice, Liverpool. However, if you feel unable to answer the questionnaire, for any reason, you can pass it on to someone else who may be better placed to complete it.
- Although we know the patient's name, for convention, we have referred to them as 's/he' in the questionnaire.

The Marie Curie Palliative Care Institute, Liverpool

- This is a partnership between the Marie Curie Hospice, Liverpool, the Royal Liverpool and Broadgreen University Hospital NHS Trust and the University of Liverpool. The key aim of the Institute is to improve the care of dying patients through research, development and education.

Content of Questionnaire

Section A:	The available facilities	Page 4
Section B	The care received from the nurses & doctors	Page 5
Section C	The control of pain & other symptoms	Page 8
Section D	The religious and spiritual support provided by the healthcare team	Page 11
Section E	The emotional support provided by the healthcare team	Page 12
Section F	Communication with the healthcare team	Page 13
Section G	The circumstances surrounding his/her death	Page 16
Section H	Overall impressions	Page 21
Section I	Information about you	Page 23
Section J	Your views on completing the questionnaire	Page 25

Instructions for completion

- As you go through the questionnaire, please follow the instructions and answer the questions by ticking the most appropriate box, like this: ✓
- Here is an example question:

B3. Did any of the doctors or nurses talk to you about stopping medicines that were no longer thought to be essential for his/her care?

Yes	<input checked="" type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

If one of the doctors or nurses had a discussion with you about stopping medicines, you would tick the 'Yes' box as in the example.

- If you would rather not or cannot answer one of the questions, please go onto the next one.
- We are very interested in what you have to say. Please continue on extra sheets if necessary.

We know s/he was cared for either at the Royal Liverpool Hospital or the Marie Curie Hospice in the days before s/he died. The questions are related to the last hours and days of his/her life, the care s/he received and your experience of that time. We would like you to reflect on this period. In particular, we would like you to focus on the last **two days** of his/her life, when answering these questions.

Section A

The available facilities

These questions are concerned with the facilities that were available for you, your family members and friends in the hospital or hospice during the last **two days** of his/her life.

Please answer the questions in the following table:

Were you, your family members or friends given <u>information</u> (either verbally or written) about the availability of the following facilities?		If <u>yes</u> , how would you rate the <u>quality</u> of these facilities? (please tick one box)				
		Poor	Fair	Good	Excellent	Don't know
A1. Food	Yes	<input type="checkbox"/>				
	No	<input type="checkbox"/>				
	Don't know	<input type="checkbox"/>				
A2. Drinks	Yes	<input type="checkbox"/>				
	No	<input type="checkbox"/>				
	Don't know	<input type="checkbox"/>				
A3. Sleeping facilities	Yes	<input type="checkbox"/>				
	No	<input type="checkbox"/>				
	Don't know	<input type="checkbox"/>				
A4. Washroom and toilet facilities	Yes	<input type="checkbox"/>				
	No	<input type="checkbox"/>				
	Don't know	<input type="checkbox"/>				
A5. Car parking facilities	Yes	<input type="checkbox"/>				
	No	<input type="checkbox"/>				
	Don't know	<input type="checkbox"/>				
A6. A family room or quiet area	Yes	<input type="checkbox"/>				
	No	<input type="checkbox"/>				
	Don't know	<input type="checkbox"/>				

A7. Did you find the visiting hours convenient?

Yes ☐
No ☐

Please feel free to comment, if you wish to, on any aspect of the facilities that were provided to you, your family members and friends:

Section B

The care received from the nurses and doctors

These questions are concerned with the general care s/he received from the doctors and nurses and the environment in which this care was delivered. The questions apply to the last **two days** of his/her life.

Please look at the following statements and tick the answer box that corresponds most with your opinion.

B1. There was enough help available to meet his/her personal care needs, such as washing, personal hygiene and toileting needs.

- | | |
|----------------------------|--------------------------|
| Strongly agree | <input type="checkbox"/> |
| Agree | <input type="checkbox"/> |
| Neither agree nor disagree | <input type="checkbox"/> |
| Disagree | <input type="checkbox"/> |
| Strongly disagree | <input type="checkbox"/> |

B2. There was enough help with nursing care, such as giving medicines and helping him/her find a comfortable position in bed.

- | | |
|----------------------------|--------------------------|
| Strongly agree | <input type="checkbox"/> |
| Agree | <input type="checkbox"/> |
| Neither agree nor disagree | <input type="checkbox"/> |
| Disagree | <input type="checkbox"/> |
| Strongly disagree | <input type="checkbox"/> |

B3. The bed area and surrounding environment was comfortable for him/her.

- | | |
|----------------------------|--------------------------|
| Strongly agree | <input type="checkbox"/> |
| Agree | <input type="checkbox"/> |
| Neither agree nor disagree | <input type="checkbox"/> |
| Disagree | <input type="checkbox"/> |
| Strongly disagree | <input type="checkbox"/> |

B4. The bed area and surrounding environment had adequate privacy for him/her.

- | | |
|----------------------------|--------------------------|
| Strongly agree | <input type="checkbox"/> |
| Agree | <input type="checkbox"/> |
| Neither agree nor disagree | <input type="checkbox"/> |
| Disagree | <input type="checkbox"/> |
| Strongly disagree | <input type="checkbox"/> |

B5. During his/her last two days, in your view, how did you find the general noise level of the ward?

- | | |
|-------------|--------------------------|
| Too noisy | <input type="checkbox"/> |
| About right | <input type="checkbox"/> |
| Too quiet | <input type="checkbox"/> |

B6. In your opinion, how clean was the ward area that s/he was in?

- | | |
|------------------|--------------------------|
| Very clean | <input type="checkbox"/> |
| Fairly clean | <input type="checkbox"/> |
| Not at all clean | <input type="checkbox"/> |

B7. How were fluids given to him/her in the last two days of his/her life?

- | | |
|--|--------------------------|
| By moistening his/her mouth with a damp sponge | <input type="checkbox"/> |
| By giving sips of water | <input type="checkbox"/> |
| By giving fluids through a 'drip' | <input type="checkbox"/> |
| No fluids were given | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |
| Other (please specify) _____ | |

B8. In your opinion, was this way of providing fluids the appropriate one?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

Please feel free to comment if you wish to: _____

B9. Did any of the doctors or nurses discuss with you whether giving fluids through a 'drip' would be appropriate in the last two days of life?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

B10. In your view, did s/he have any unnecessary tests or checks (for example too many blood tests or blood pressure checks)?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

B11. Did any of the doctors or nurses talk to you about stopping medicines that were no longer thought to be essential for his/her care?

- Yes ☐
- No ☐
- Don't know ☐

If yes: Were you given reasons for these decisions?

- Yes ☐
- No ☐

Please feel free to comment if you wish to: _____

B12. Did you have confidence and trust in the nurses who were caring for him/her?

- Yes, in all of them ☐
- Yes, in some of them ☐
- No, not in any of the nurses ☐

B13. Did you have confidence and trust in the doctors who were caring for him/her?

- Yes, in all of them ☐
- Yes, in some of them ☐
- No, not in any of the doctors ☐

B14. Overall, how would you assess the care s/he received from the nurses?

- Excellent ☐
- Good ☐
- Fair ☐
- Poor ☐

B15. Overall, how would you assess the care s/he received from the doctors?

- Excellent ☐
- Good ☐
- Fair ☐
- Poor ☐

Please feel free to comment, if you wish to, on any aspect of the care s/he received or the environment in which this care was delivered:

Section C

The control of pain & other symptoms

These questions are concerned with the symptoms s/he had and the care s/he received during the last two days of his/her life.

C1. Many people are unconscious or drowsy towards the end of their life.
In his/her last two days, was s/he unconscious or drowsy?

- Yes ☐
- No ☐
- Don't know ☐

C2. Did you want to continue talking and interacting with him/her even when s/he seemed to be unconscious?

- Yes ☐
- No ☐
- Don't know ☐
- Not applicable ☐

If yes: did the doctors or nurses support and help you do this?

- Yes ☐
- No ☐

Please feel free to comment if you wish to: _____

C3. In your opinion, during the last two days, did s/he appear to be in pain?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not appear to be in pain ☐

C4. When s/he was in pain, was it usually mild, moderate or severe?

- Mild ☐
- Moderate ☐
- Severe ☐
- Don't know ☐
- Not applicable, s/he was not in pain ☐

C5. In your view, did the doctors and nurses do enough to help relieve the pain?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, not at all ☐
- Not applicable, s/he was not in pain ☐

Please feel free to comment if you wish to: _____

C6. In your opinion, during the last two days, did s/he appear to be restless?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not appear to be restless ☐

C7. In your view, should more have been done by the doctors and nurses to help relieve his/her restlessness?

- Yes ☐
- No ☐
- Not applicable, s/he was not restless ☐

Please feel free to comment if you wish to: _____

C8. In your opinion, during the last two days, did s/he appear to have a 'noisy rattle' to his/her breathing?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not have a 'noisy rattle' to the breathing ☐

C9. In your view, should more have been done by the doctors and nurses to help relieve the 'noisy rattle' to his/her breathing?

- Yes ☐
- No ☐
- Not applicable, s/he did not have a 'noisy rattle' to the breathing ☐

Please feel free to comment if you wish to: _____

C10. In your opinion, during these last two days, did s/he have any nausea and/or vomiting? By the term 'nausea', we mean 'feeling sick'.

- | | |
|---|--------------------------|
| Yes, all of the time | <input type="checkbox"/> |
| Yes, some of the time | <input type="checkbox"/> |
| No, s/he did not have nausea and vomiting | <input type="checkbox"/> |

C11. In your view, should the doctors and nurses have done more to help relieve the nausea and vomiting?

- | | |
|---|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Not applicable, s/he did not have nausea and vomiting | <input type="checkbox"/> |

Please feel free to comment if you wish to: _____

C12. In your opinion, during the last two days, did s/he appear breathless?

- | | |
|------------------------------------|--------------------------|
| Yes, all of the time | <input type="checkbox"/> |
| Yes, some of the time | <input type="checkbox"/> |
| No, s/he did not appear breathless | <input type="checkbox"/> |

C13. In your view, should more have been done by the doctors and nurses to relieve the breathlessness?

- | | |
|---|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Not applicable, s/he was not breathless | <input type="checkbox"/> |

Please feel free to comment if you wish to: _____

C14. In your opinion, should the doctors and nurses have done more to keep his/her mouth moist and clean?

- | | |
|---|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |
| Not applicable, his/her mouth was moist and clean | <input type="checkbox"/> |

Please feel free to comment, if you wish to, on any other symptoms s/he may have had and any help s/he may have received for these:

Section D

The religious and spiritual support provided by the healthcare team

The following questions are about the religious and spiritual support that was provided to you and your family member or friend by the healthcare team in the last **two days** of his/her life. By **‘healthcare team’**, we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain.

Please look at the following statements and tick the answer box that corresponds most with your opinion.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know / Not applicable
D1. The healthcare team talked to him/her about their religious and/or spiritual beliefs.						
D2. S/he was able to receive support from a religious or spiritual leader.						
D3. When providing care, the healthcare team took his/her religious and/or spiritual beliefs into consideration.						
D4. The healthcare team talked to <u>you</u> about your religious and/or spiritual beliefs.						
D5. The healthcare team provided <u>you</u> with religious and/or spiritual support.						
D6. <u>You</u> were able to receive support from a religious or spiritual leader.						
D7. The healthcare team asked in advance about specific religious and/or spiritual rituals that <u>you</u> wanted at the time of his/her death.						

Please feel free to comment, if you wish to, on any aspect of the religious and/or spiritual support received:

Section E

The emotional support provided by the healthcare team

The following questions are about the level of emotional support that was provided to you, your family members and friends in the last **two days** of his/her life by the healthcare team. By **‘healthcare team’**, we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain.

E1. Did s/he have any unresolved emotional issues in the last two days of life?

- Yes☐
- No☐
- Not sure☐

Please feel free to comment if you wish to: _____

E2. Were you given the opportunity to discuss your concerns about support for children who were most affected by his/her dying and death?

- Yes☐
- No☐
- Not applicable☐

E3. Were you given the opportunity to discuss any practical or legal concerns with the healthcare team (for example finances, wills)?

- Yes☐
- No☐
- Not applicable☐

E4. How would you assess the overall level of emotional support given to you by the healthcare team?

- Poor☐
- Fair☐
- Good☐
- Excellent☐

Please feel free to comment, if you wish to, on any aspect of the emotional issues and support received:

Section F

Communication with the healthcare team

These questions are about the communication and information that you, your family members and friends received from the healthcare team in the last **two days** of his/her life. By **‘healthcare team’**, we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain.

F1. Did s/he have any communication difficulties (for example difficulties with hearing or difficulties with speaking English)?

- Yes ☐
- No ☐
- Don't know ☐

F2. Did any of the healthcare team ask if s/he had any communication difficulties?

- Yes ☐
- No ☐
- Don't know ☐

F3. Do you have any communication difficulties?

- Yes ☐
- No ☐

F4. Did any of the healthcare team ask if you have any communication difficulties?

- Yes ☐
- No ☐

Please feel free to comment if you wish to: _____

F5. Was it clear how you should contact the hospital or hospice (for example if you wanted to know if there was any change in his/her condition)?

- Yes ☐
- No ☐
- Not applicable ☐

F6. Did the hospital or hospice know how to get in contact with you or another family member (for example if his/her condition changed suddenly and the healthcare team wanted to let you know)?

- Yes ☐
- No ☐
- Not sure ☐

F7. During the last two days, how involved were you with the decisions about his/her care and treatment?

- | | |
|-----------------|--------------------------|
| Very involved | <input type="checkbox"/> |
| Fairly involved | <input type="checkbox"/> |
| Not involved | <input type="checkbox"/> |

F8. Were you involved in decisions about his/her care and treatment as much as you wanted?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

F9. Was there any decision made about his/her care or treatment that you did not want?

- | | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |
| Don't know | <input type="checkbox"/> |

Please feel free to comment if you wish to: _____

F10. Did the healthcare team explain his/her condition and/or treatment in a way you found easy or difficult to understand?

- | | |
|---|--------------------------|
| Very easy | <input type="checkbox"/> |
| Fairly easy | <input type="checkbox"/> |
| Fairly difficult | <input type="checkbox"/> |
| Very difficult | <input type="checkbox"/> |
| They did not explain his/her condition or treatment to me | <input type="checkbox"/> |

F11. Did any of the healthcare team ask about your understanding of what was happening?

- | | |
|-----|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |

F12. Were you able to discuss with the healthcare team any worries or fears you had about his/her condition and/or treatment?

- | | |
|-----|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |

Please look at the following statements and tick the answer box that corresponds most with your opinion.

F13. The doctors had time to listen and discuss his/her condition with me.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

F14. The nurses had time to listen and discuss his/her condition with me.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

F15. Did it ever happen that one doctor or nurse said one thing about his/her condition and treatment and another said something different?

- Yes, often ☐
- Yes, sometimes ☐
- Yes, once ☐
- No, never ☐

F16. In your opinion, did the healthcare team ever deliberately not tell you certain things you wanted to know?

- Yes, often ☐
- Yes, sometimes ☐
- Yes, once ☐
- No, never ☐

Please feel free to comment, if you wish to, on any aspect of the communication or information you, your family members or friends received:

Section G

The circumstances surrounding his/her death

The following questions are about the circumstances surrounding his/her death, and your feelings about the way in which the healthcare team treated you both at this time. By **‘healthcare team’**, we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain.

G1. Before s/he died, were you told s/he was likely to die soon?

- Yes☐
- No☐

If **‘Yes’**, who told you s/he was likely to die soon? _____
Please continue with the questions below.

- **If ‘No’, please go to question G6 (on the next page)**

G2. At that time, were you given the chance to talk about the fact that s/he was dying?

- Yes☐
- No☐
- Don't know☐

G3. Was that the first time you were aware that s/he was dying?

- Yes☐
- No☐
- Don't know☐

G4. Did you have enough privacy when you were told that s/he was dying?

- Yes☐
- No☐
- Don't know☐

G5. Were you told in a sensitive manner?

- Yes☐
- No☐
- Don't know☐

Please feel free to comment if you wish to: _____

G6. Were you given any written information about what to expect when s/he was dying?

Yes ☐
No ☐

If yes: Was this in a way that was easy to understand?

Yes ☐
No ☐

Please feel free to comment if you wish to: _____

G7. Did a member of the healthcare team talk to you about what would happen at the time of his/her death?

Yes ☐
No ☐

If yes: was this in a way that was easy to understand?

Yes ☐
No ☐

Please feel free to comment if you wish to: _____

G8. Where did s/he die?

Hospital ☐
Hospice ☐
Other (please specify): _____

G9. In your opinion did s/he die in the right place?

Yes, it was the right place ☐
No, it was not the right place ☐
Not sure ☐
Don't know ☐

If no: please tell us why it wasn't the right place

G10. Were you asked if you wanted to be present when s/he died?

- Yes ☐
- No ☐

G11. Were you with him/her when s/he died?

- Yes ☐
- No ☐

Please feel free to comment if you wish to: _____

Please look at the following statements and tick the answer box that corresponds most with your opinion.

G12. I was given enough help and support by the healthcare team at the actual time of his/her death.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

G13. His/her personal belongings were returned to the family (or friend) in a sensitive manner.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

G14. Were particular practices or rituals followed after his/her death that were important to you, your family members or friends?

- Yes ☐
- No ☐
- Don't know ☐
- Not applicable ☐

Please feel free to comment if you wish to: _____

G15. After s/he had died, did you receive any written information about what to do next, for example registering the death and organising the funeral?

Yes ☐
No ☐

If yes: Was this useful?

Yes ☐
No ☐

G16. Did you receive any written information about what you might experience after s/he had died (for example a bereavement leaflet)?

Yes ☐
No ☐

If yes: Was this useful?

Yes ☐
No ☐

G17. Since s/he died have you talked to anyone from health or social services or from a bereavement service about your experiences regarding the illness and death?

Yes ☐
No ☐
Don't know ☐

If yes: Was that talk helpful?

Yes ☐
No ☐

Please feel free to comment, if you wish to: _____

G18. Since s/he died, have individuals from the healthcare team dealt with you in a sensitive manner?

Yes ☐
No ☐
Not applicable, I haven't had any contact with the healthcare team ☐

**G19. Since s/he died, have you been in any situation in which there appeared to be a lack of communication about his/her death?
For example, your GP not being aware s/he had died or outpatient appointment cards being sent out after s/he had died.**

Yes ☐
No ☐

Please feel free to comment if you wish to: _____

Please feel free to comment, if you wish to, on any aspect of care received around the time of his/her death and in the time since his/her death:

Section H

Overall impressions

The following questions are about your overall impression of the care s/he received in the last **two days** of life and your experiences during that time.

H1. How much of the time was s/he treated with respect and dignity by the healthcare team?

- Always ☐
- Most of the time ☐
- Some of the time ☐
- Never ☐
- Don't know ☐

H2. How much of the time was s/he treated as an individual by the healthcare team?

- Always ☐
- Most of the time ☐
- Some of the time ☐
- Never ☐
- Don't know ☐

H3. In his/her last two days, in your opinion, was s/he at peace?

- Yes ☐
- No ☐
- Don't know ☐

Please feel free to comment if you wish to: _____

H4. Overall, in your opinion, did s/he have a dignified death?

- Yes ☐
- No ☐

Please feel free to comment, if you wish to: _____

H5. Overall, in your opinion, were you adequately supported during his/her last two days of life?

- Yes

☐
- No

☐

Please feel free to comment if you wish to: _____

Please feel free to comment, if you wish to, on any aspect of the overall care and support received:

Section I

Information about you

We would like to know a little more about you. This will help us make further use of the information you give us.

I1. What was your relationship to him/her?

Were you his/her:

- Husband / Wife / Partner ☐
- Son / Daughter ☐
- Brother / Sister ☐
- Son-in-law / Daughter-in-law ☐
- Parent ☐
- Friend ☐
- Neighbour ☐
- Staff in nursing or residential home ☐
- Warden (sheltered accommodation) ☐
- Other (please describe) _____ ☐

I2. What age group are you in?

- 18 – 19 ☐
- 20 – 29 ☐
- 30 – 39 ☐
- 40 – 49 ☐
- 50 – 59 ☐
- 60 – 69 ☐
- 70 – 79 ☐
- 80 + ☐

I3. Please could you indicate to which ethnic group you belong:

- | | | | |
|------------------------------|--------------------------|-------------------------------|--------------------------|
| White British | <input type="checkbox"/> | Mixed white / black Caribbean | <input type="checkbox"/> |
| White Irish | <input type="checkbox"/> | Mixed white / black African | <input type="checkbox"/> |
| White other | <input type="checkbox"/> | Mixed white / Asian | <input type="checkbox"/> |
| Indian | <input type="checkbox"/> | Mixed other | <input type="checkbox"/> |
| Pakistani | <input type="checkbox"/> | Black Caribbean | <input type="checkbox"/> |
| Bangladeshi | <input type="checkbox"/> | Black African | <input type="checkbox"/> |
| Asian other (please specify) | <input type="checkbox"/> | Black other (please specify) | <input type="checkbox"/> |

None of these (please specify)

I4. Are you:

- Male ☐
Female ☐

I5. What is your religious affiliation?

- None ☐
Buddist ☐
Christian ☐
Jewish ☐
Hindu ☐
Muslim ☐
Sikh ☐
None of these (please specify)

I6. Would you like to receive a copy of the report following the completion of this study (estimated July 2007)?

- Yes ☐
No ☐

Section J

Your views on completing the questionnaire

We understand that this questionnaire is about a sensitive topic and we are grateful to you for filling it in. We think it is important to know the views of relatives and friends so that your views can be taken into account when improving services and care. But we want to be sure that we are asking you about your views in the most sensitive way. We would like to learn about your experience of completing this questionnaire.

J1. Did you find any aspect of the questionnaire upsetting?

- Yes☐
- No☐

If yes, could you tell us more about this?

J2. What do you think about the length of the questionnaire? Is it:

- Too long☐
- Just right☐
- Too short☐
- Ok☐
- Other (please specify)

J3. Are there any questions you think we should have left out?

- Yes☐
- No☐

If yes, could you tell us more about this?

J4. Are there any questions you think we should add?

- Yes☐
- No☐

If yes, could you tell us more about this?

**Thank you very much for taking the time to complete
this questionnaire.**

**We would be very grateful if you could return it to us in the stamped
address envelope provided, or post to:**

**Dr Catriona Mayland
Clinical Research Fellow
Directorate of Specialist Palliative Care
1st Floor, Linda McCartney Centre
Royal Liverpool University Hospital
Prescot Street
Liverpool
L7 8XP**

Appendix 8: Interview briefing sheet

Purpose of the interview

The interview is to help improve the quality of the questionnaire. We want to ensure the questions are worded clearly, easy to understand and are expressed in a sensitive manner.

Structure of the interview

The interview will sequentially go through the questionnaire.

For each page of the questionnaire, I will ask you about some of the questions.

1. Firstly I will ask you some general questions about the questionnaire. This may include aspects such as how you found the layout or wording of the questions.
2. Then I will ask you some more detailed questions.
We may use the **'think aloud'** process. This method encourages you to articulate or 'think aloud' your thoughts as you read and answer a question.
Alternatively, I may just ask you more detailed questions about how you found the questionnaire to complete and what certain terms meant to you.
3. Finally, you will have the opportunity to raise any other issues about questions that we haven't already discussed.

Appendix 9: Consent form (pilot)

Participant Identification Number for this study:

CONSENT FORM

Title of Project: How well do we care for dying patients? Assessing relatives' views regarding the quality of care at the end-of-life.

Name of Researcher: Dr Catriona Mayland

Contact details: Clinical Research Fellow in Palliative Medicine, Directorate of Palliative Care,
Royal Liverpool Hospital, Liverpool.
Tel: 0151 706 2274
Email: catriona.mayland@rlbuht.nhs.uk

Please initial box

1. I confirm that I have read and understand the information sheet dated 11th November 2005 (version 1.4) for the above study and have had the opportunity to ask questions.

☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

☐
3. I agree to allow the interview to be tape-recorded and that this recording can be used to form a written account of the interview.

☐
4. I agree to take part in the above study.

☐

Name of Participant

Date

Signature

Researcher

Date

Signature

1 for participant; 1 for researcher

ECHO-D

Evaluating Care & Health Outcomes - for the Dying

- This is a questionnaire about the care received by people in the last hours and days of life and the experiences of their families and friends during that time.
- The team at the Marie Curie Palliative Care Institute consider the care of dying patients to be a priority. We also think it is important to find out more about the care and support you, your family and friends received at the time of death. Your views are, therefore, important to us. Please fill in as much of the questionnaire as you can.
- We realise this questionnaire may bring back strong memories and emotions and that reading it for the first time may be difficult. You may wish to wait and find someplace quiet to read the questionnaire. If you feel upset or distressed in any way, you do not have to continue with the questionnaire and can stop at any time. However, if you wish to, you can return to the questionnaire at a future time.

**Your answers will, of course, be treated as strictly confidential.
Individuals will not be identifiable in the reports we write.**

- You have been sent this questionnaire as you are registered as the next of kin to a patient who died in the Royal Liverpool & Broadgreen University Hospitals or the Marie Curie Hospice, Liverpool. However, if you feel unable to answer the questionnaire, for any reason, you can pass it on to someone else who may be better placed to complete it.
- Although we know the patient's name, for convention, we have referred to them as 's/he' in the questionnaire.

The Marie Curie Palliative Care Institute, Liverpool

- This is a partnership between the Marie Curie Hospice, Liverpool, the Royal Liverpool and Broadgreen University Hospital NHS Trust and the University of Liverpool. The key aim of the Institute is to improve the care of dying patients through research, development and education.

Content of Questionnaire

Section A	The available facilities	Page 4
Section B	The care received from the nurses & doctors	Page 5
Section C	The control of pain & other symptoms	Page 8
Section D	The religious and spiritual support provided by the healthcare team	Page 11
Section E	Communication and emotional support	Page 13
Section F	The circumstances surrounding his/her death	Page 16
Section G	Overall impressions	Page 21
Section H	Information about you	Page 23
Section I	Your views on completing the questionnaire	Page 25

Instructions for completion

- As you go through the questionnaire, please follow the instructions and answer the questions by crossing the most appropriate box, like this: [x]
- Here is an example question:

B10. In your view, did s/he have any unnecessary tests or checks (for example too many blood tests or blood pressure checks)?

Yes	<input checked="" type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

If, in your opinion, your family member or friend had unnecessary tests or checks, you would cross the 'Yes' box as in the example.

- If you would rather not or cannot answer one of the questions, please go onto the next one.
- We are very interested in what you have to say. Please continue on extra sheets if necessary.

We know s/he was cared for either at the Royal Liverpool and Broadgreen Hospitals or the Marie Curie Hospice in the days before s/he died. The questions are related to the last hours and days of his/her life, the care s/he received and your experience of that time. We would like you to reflect on this period. In particular, we would like you to focus on the last **two days** of his/her life, when answering these questions.

Section A: The available facilities

These questions are concerned with the facilities that were available for you, your family members and friends in the hospital or hospice during the last **two days** of his/her life.

Please answer the questions in the following table:

Were you, your family members or friends given information (either verbally or written) about the availability of the following facilities?			How would you rate the quality of these facilities? (please cross one box [x])				
			Poor	Fair	Good	Excellent	Don't know
A1. A family room or quiet area	Yes	<input type="checkbox"/>					
	No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Don't know	<input type="checkbox"/>					
A2. Car parking facilities	Yes	<input type="checkbox"/>					
	No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Don't know	<input type="checkbox"/>					
A3. Sleeping facilities	Yes	<input type="checkbox"/>					
	No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Don't know	<input type="checkbox"/>					
A4. Washroom and toilet facilities	Yes	<input type="checkbox"/>					
	No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Don't know	<input type="checkbox"/>					
A5. Food	Yes	<input type="checkbox"/>					
	No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Don't know	<input type="checkbox"/>					
A6. Drinks	Yes	<input type="checkbox"/>					
	No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Don't know	<input type="checkbox"/>					

A7. Did you find the visiting hours convenient?

Yes ☐

No ☐

Please feel free to comment, if you wish to, on any aspect of the facilities that were provided to you, your family members and friends:

Section B: The care received from the nurses and doctors

These questions are concerned with the general care s/he received from the doctors and nurses and the environment in which this care was delivered. The questions apply to the last **two days** of his/her life.

Please look at the following statements and cross [X] the answer box that corresponds most with your opinion.

B1. There was enough help available to meet his/her personal care needs, such as washing, personal hygiene and toileting needs.

- Strongly Agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

B2. There was enough help with nursing care, such as giving medicines and helping him/her find a comfortable position in bed.

- Strongly Agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

B3. The bed area and surrounding environment was comfortable for him/her.

- Strongly Agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

B4. The bed area and surrounding environment had adequate privacy for him/her.

- Strongly Agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

B5. During his/her last two days, in your view, how did you find the general noise level of the ward?

- Too noisy
- ☐
- About right
- ☐
- Too quiet
- ☐

B6. In your opinion, how clean was the ward area that s/he was in?

- Very clean
- ☐
- Fairly clean
- ☐
- Not at all clean
- ☐

B7. How were fluids given to him/her in the last two days of his/her life?

- By moistening his or her mouth with a damp sponge
- ☐
- By giving sips of water
- ☐
- By giving fluids through a 'drip'
- ☐
- No fluids were given
- ☐
- Don't know
- ☐
- Other (please specify) _____
- ☐

B8. In your opinion, was this way of providing fluids the appropriate one?

- Yes
- ☐
- No
- ☐
- Don't know
- ☐

Please feel free to comment if you wish to: _____

B9. Did any of the doctors or nurses discuss with you the appropriateness of giving fluids through a 'drip' in the last two days of life?

- Yes
- ☐
- No
- ☐
- Don't know
- ☐

If no: Would these types of discussion have been helpful?

- Yes
- ☐
- No
- ☐

Please feel free to comment if you wish to: _____

B10. In your view, did s/he have any unnecessary tests or checks (for example too many blood tests or blood pressure checks)?

- Yes ☐
- No ☐
- Don't know ☐

B11. Did you have confidence and trust in the nurses who were caring for him/her?

- Yes, in all of them ☐
- Yes, in some of them ☐
- No, not in any of the nurses ☐

B12. Did you have confidence and trust in the doctors who were caring for him/her?

- Yes, in all of them ☐
- Yes, in some of them ☐
- No, not in any of the nurses ☐

B13. Overall, how would you assess the care s/he received from the nurses?

- Excellent ☐
- Good ☐
- Fair ☐
- Poor ☐

B14. Overall, how would you assess the care s/he received from the doctors?

- Excellent ☐
- Good ☐
- Fair ☐
- Poor ☐

Please feel free to comment, if you wish to, on any aspect of the care s/he received or the environment in which this care was delivered:

Section C: The control of pain and other symptoms

These questions are concerned with the symptoms s/he had and the care s/he received during the last **two days** of his/her life.

C1. Many people are unconscious or drowsy towards the end of their life. In his/her last two days, was s/he unconscious or drowsy?

- Yes ☐
- No ☐
- Don't know ☐

C2. Did you want to continue talking and interacting with him/her even when s/he seemed to be unconscious?

- Yes ☐
- No ☐
- Don't know ☐
- Not applicable ☐

If yes: Did the doctors or nurses support and help you do this?

- Yes ☐
- No ☐

Please feel free to comment if you wish to: _____

C3. In your opinion, during the last two days, did s/he appear to be in pain?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not appear to be in pain ☐

C4. During the last two days when s/he was in pain, was it usually mild, moderate or severe?

- Mild ☐
- Moderate ☐
- Severe ☐
- Don't know ☐
- Not applicable, s/he was not in pain ☐

C5. In your view, did the doctors and nurses do enough to help relieve the pain?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, not at all ☐
- Not applicable, s/he was not in pain ☐

Please feel free to comment if you wish to: _____

C6. In your opinion, during the last two days, did s/he appear to be restless?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not appear to be restless ☐

C7. In your view, should more have been done by the doctors and nurses to help relieve his/her restlessness?

- Yes ☐
- No ☐
- Not applicable, s/he was not restless ☐

Please feel free to comment if you wish to: _____

C8. In your opinion, during the last two days, did s/he appear to have a 'noisy rattle' to his/her breathing?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not have a 'noisy rattle' to the breathing ☐

C9. Did you find the 'noisy rattle' to his/her breathing distressing?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, not at all ☐
- Not applicable, there was no 'noisy rattle' to his/her breathing ☐

C10. In your view, should more have been done by the doctors and nurses to help relieve the 'noisy rattle' to his/her breathing?

- Yes ☐
- No ☐
- Not applicable, there was no 'noisy rattle' to his/her breathing ☐

Please feel free to comment if you wish to: _____

**C11. In your opinion, during these last two days, did s/he have any nausea and/or vomiting?
By the term 'nausea', we mean 'feeling sick'.**

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not have nausea and vomiting ☐

C12. In your view, should the doctors and nurses have done more to help relieve the nausea and vomiting?

- Yes ☐
- No ☐
- Not applicable, s/he did not have nausea and vomiting ☐

Please feel free to comment if you wish to: _____

C13. In your opinion, during the last two days, did s/he appear breathless?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not appear breathless ☐

C14. In your view, should more have been done by the doctors and nurses to relieve the breathlessness?

- Yes ☐
- No ☐
- Not applicable, s/he was not breathless ☐

Please feel free to comment if you wish to: _____

C15. In your opinion, should the doctors and nurses have done more to keep his/her mouth moist and clean?

- Yes ☐
- No ☐
- Don't know ☐
- Not applicable, his/her mouth was moist and clean ☐

Please feel free to comment, if you wish to, on any other symptoms s/he may have had and any help s/he may have received for these:

Section D: The religious and spiritual support provided by the healthcare team

The following questions are about the religious and spiritual support that was provided to you and your family member or friend by the healthcare team in the last **two days** of his/her life. By **'healthcare team'**, we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain.

Please look at the following statements and cross [x] the answer box that corresponds most with your opinion.

D1. Did the healthcare team talk to him/her about their religious or spiritual beliefs?

- Yes☐
- No☐
- Don't know☐

D2. Did the healthcare team talk to you about your religious or spiritual beliefs?

- Yes☐
- No☐

D3. Was s/he offered support from a religious or spiritual leader?

- Yes☐
- No☐
- Don't know☐

D4. Were you offered support from a religious or spiritual leader?

- Yes☐
- No☐

D5. Did the healthcare team ask in advance about specific religious or spiritual rituals that you wanted at the time of his/her death?

- Yes☐
- No☐

Please look at the following statements and cross [x] the answer box that corresponds most with your opinion.

D6. Overall, his/her religious or spiritual needs were met by the healthcare team.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

D7. Overall, my religious or spiritual needs were met by the healthcare team.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

Please feel free to comment, if you wish to, on any aspect of the religious and/or spiritual support received:

Section E: Communication and emotional support

The following questions are about the communication and information that you, your family members and friends received from the healthcare team in the last **two days** of his/her life. We also want to know about the level of emotional support that was provided by the healthcare team. By **'healthcare team'**, we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain

E1. Was it clear how you should contact the hospital or hospice (for example if you wanted to know if there was any change in his/her condition)?

- Yes☐
- No☐
- Not applicable☐

E2. Did the hospital or hospice know how to get in contact with you or another family member (for example if his/her condition changed suddenly and the healthcare team wanted to let you know)?

- Yes☐
- No☐
- Not sure☐

E3. During the last two days, how involved were you with the decisions about his/her care and treatment?

- Very involved☐
- Fairly involved☐
- Not involved☐

E4. Were you involved in decisions about his/her care treatment as much as you wanted?

- Yes☐
- No☐
- Don't know☐

E5. Was there any decision made about his/her care or treatment that you did not want?

- Yes☐
- No☐
- Don't know☐

Please feel free to comment if you wish to: _____

E6. Did the healthcare team explain his/her condition and/or treatment in a way that you found easy or difficult to understand?

- Very easy ☐
- Fairly easy ☐
- Fairly difficult ☐
- Very difficult ☐
- They did not explain his/her condition or treatment to me ☐

E7. Did any of the healthcare team ask you about your understanding of what was happening?

- Yes ☐
- No ☐

E8. Would the offer of a translator have been useful?

- Yes ☐
- No ☐
- Not applicable ☐

E9. In your opinion, did s/he have any unresolved emotional issues in the last two days of life?

- Yes ☐
- No ☐
- Not sure ☐

Please feel free to comment if you wish to: _____

E10. Were you able to discuss with the healthcare team any worries or fears you had about his/her condition and/or treatment?

- Yes ☐
- No ☐

E11. Were you given the opportunity to discuss your concerns about support for children or grandchildren (under the age of 18 years) who were most affected by his/her dying and death?

- Yes ☐
- No ☐
- Not applicable ☐

If no: Would this type of support have been useful?

- Yes ☐
- No ☐

E12. Did it ever happen that one doctor or nurse said one thing about his/her condition and treatment and another said something different?

- Yes, often ☐
- Yes, sometimes ☐
- Yes, once ☐
- No, never ☐

E13. In your opinion, did the healthcare team ever deliberately not tell you certain things you wanted to know?

- Yes, often ☐
- Yes, sometimes ☐
- Yes, once ☐
- No, never ☐

Please look at the following statements and cross [X] the answer box that corresponds most with your opinion.

E14. The doctors had time to listen and discuss his/her condition with me.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

E15. The nurses had time to listen and discuss his/her condition with me.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

E16. How would you assess the overall level of emotional support given to you by the healthcare team?

- Poor ☐
- Fair ☐
- Good ☐
- Excellent ☐

Please feel free to comment, if you wish to, on any aspect of the level of communication, information, or emotional support you, your family member or friend received:

Section F: The circumstances surrounding his/her death

The following questions are about the circumstances surrounding his/her death, and your feelings about the way in which the healthcare team treated you both at this time. By 'healthcare team', we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain.

F1. Before s/he died, were you told s/he was likely to die soon?

- Yes☐
- No☐

If 'Yes', who told you s/he was likely to die soon?
Please continue with the questions below.

- If 'No', please go to question F6 (on the next page)

F2. At that time, were you given the chance to talk about the fact that s/he was dying?

- Yes☐
- No☐
- Don't know☐

F3. Was that the first time you were aware s/he was dying?

- Yes☐
- No☐
- Don't know☐

F4. Did you have enough privacy when you were told s/he was dying?

- Yes☐
- No☐
- Don't know☐

F5. Were you told in a sensitive manner?

- Yes☐
- No☐
- Don't know☐

Please feel free to comment if you wish to:

F6. Were you given any written information about what to expect when s/he was dying?

Yes ☐
No ☐

If yes: Was this in a way that was easy to understand?

Yes ☐
No ☐

If no: Would this type of information have been useful?

Yes ☐
No ☐

Please feel free to comment if you wish to: _____

F7. Did a member of the healthcare team talk to you about what would happen at the time of his/her death?

Yes ☐
No ☐

If no: Would this type of discussion have been useful?

Yes ☐
No ☐

Please feel free to comment if you wish to: _____

F8. Did s/he ever express a preference about where s/he would like to die?

Yes (if possible, please specify place) _____ ☐
No ☐

If yes: Was this ever discussed with the healthcare team?

Yes ☐
No ☐
Don't know ☐

F9. Where did s/he die?

Hospice ☐
Hospital ☐
Other (please specify) _____ ☐

F10. In your opinion did s/he die in the right place?

- Yes, it was in the right place ☐
- No, it was not in the right place ☐
- Not sure ☐
- Don't know ☐

If no: please tell us why it wasn't the right place

F11. Were you asked if you wanted to be present when s/he died?

- Yes ☐
- No ☐

F12. Were you with him/her when s/he died?

- Yes ☐
- No ☐

Please feel free to comment if you wish to:

Please look at the following statements and cross [X] the answer box that corresponds most with your opinion.

F13. I was given enough help and support by the healthcare team at the actual time of his/her death.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

F14. His/her personal belongings were returned to the family (or friend) in a sensitive manner.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

F15. Were particular practices or rituals followed after his/her death that were important to you, your family members or friends?

- Yes ☐
- No ☐
- Don't know ☐
- Not applicable ☐

Please feel free to comment if you wish to: _____

F16. After s/he had died, did you or another family member or friend receive any written information about what to do next for example registering the death and organising the funeral?

- Yes ☐
- No ☐

If yes: was this useful?

- Yes ☐
- No ☐

F17. Did you receive any written information about what you might experience after s/he had died (for example a bereavement or grieving leaflet)?

- Yes ☐
- No ☐

If yes: was this useful?

- Yes ☐
- No ☐

F18. Since s/he died have you talked to anyone from health or social services or from a bereavement service about your experiences regarding the illness and death?

- Yes ☐
- No ☐
- Don't know ☐

If yes: was that talk helpful?

- Yes ☐
- No ☐

Please feel free to comment if you wish to: _____

F19. Since s/he died, have individuals from the healthcare team dealt with you in a sensitive manner?

- Yes ☐
- No ☐
- Not applicable, I haven't had any contact with the healthcare team ☐

**F20. Since s/he died, have you been in any situation in which there appeared to be a lack of communication about his/her death?
For example, your GP not being aware s/he had died or outpatient appointment cards being sent out after s/he had died.**

- Yes ☐
- No ☐

Please feel free to comment if you wish to: _____

Please feel free to comment, if you wish to, on any aspect of care received around the time of his/her death and in the time since his/her death:

Section G: Overall Impressions

The following questions are about your impression of the care s/he received in the last **two days** of life and your experiences during that time

G1. How much of the time was s/he treated with respect and dignity by the healthcare team?

- Always ☐
- Most of the time ☐
- Some of the time ☐
- Never ☐
- Don't know ☐

G2. How much of the time was s/he treated as an individual by the healthcare team?

- Always ☐
- Most of the time ☐
- Some of the time ☐
- Never ☐
- Don't know ☐

G3. In his/her last two days, in your opinion, was s/he at peace?

- Yes ☐
- No ☐
- Don't know ☐

Please feel free to comment if you wish to: _____

G4. Overall, in your opinion, did s/he have a dignified death?

- Yes ☐
- No ☐

Please feel free to comment if you wish to: _____

G5. Overall, in your opinion, were you adequately supported by the healthcare team during his/her last two days of life?

- Yes☐
- No☐

Please feel free to comment if you wish to: _____

Please feel free to comment, if you wish to, on any aspect of the overall care and support received:

Section H: Information about you

We would like to know a little more about you. This will help us make further use of the information you give us.

H1. What was your relationship to him/her?

Were you his/her:

- Husband / Wife / Partner☐
- Son / Daughter☐
- Brother / Sister☐
- Son-in-law / Daughter-in-law☐
- Parent☐
- Friend☐
- Neighbour☐
- Staff in a nursing or residential home☐
- Warden (sheltered accommodation)☐
- Other (please describe) ☐

H2. What age group are you in?

- 18-19☐
- 20-29☐
- 30-39☐
- 40-49☐
- 50-59☐
- 60-69☐
- 70-79☐
- 80+☐

H3. Please could you indicate to which ethnic group you belong:

- White British☐

Mixed white / black Caribbean☐
- White Irish☐

Mixed white / black African☐
- White other☐

Mixed white / Asian☐
- Indian☐

Mixed other☐
- Pakistani☐

Black Caribbean☐
- Bangladeshi☐

Black African☐
- Asian other (please specify) ☐

Black other (please specify) ☐

None of these (please specify) ☐

H4. Are you:

- Male ☐
- Female ☐

H5. What is your religious affiliation?

- None ☐
- Buddhist ☐
- Christian ☐
- Jewish ☐
- Hindu ☐
- Muslim ☐
- Sikh ☐
- None of these (please specify) ☐
-

H6. Would you like to receive a copy of the report following the completion of this study (estimated July 2007)?

- Yes ☐
- No ☐

Section I: Your views on completing the questionnaire

We understand that this questionnaire is about a sensitive topic and we are grateful to you for filling it in. We think it is important to know the views of relatives and friends so that your views can be taken into account when improving services and care. But we want to be sure that we are asking you about your views in the most sensitive way. We would like to learn about your experience of completing this questionnaire.

I1. Did you find any aspect of the questionnaire upsetting?

- Yes☐
- No☐

If yes, could you tell us more about this?

I2. What did you think about the length of the questionnaire? Is it:

- Too long☐
- Just right☐
- Too short☐
- Ok☐
- Other (please specify)☐

I3. Are there any questions you think we should have left out?

- Yes☐
- No☐

If yes, could you tell us more about this?

I4. Are there any questions you think we should add?

- Yes☐
- No☐

If yes, could you tell us more about this?

**Thank you very much for taking the time to
complete this questionnaire.**

**We would be very grateful if you could return it to us in the
freepost envelope provided, or post to:**

**Dr Catriona Mayland
Clinical Research Fellow
Directorate of Specialist Palliative Care
1st Floor, Linda McCartney Centre
Royal Liverpool University Hospital
Prescot Street
Liverpool
L7 8XP**

Appendix 11: Letter of invitation (main study)

Marie Curie Palliative Care Institute
Directorate of Palliative Care
Royal Liverpool Hospital
Prescot Road
Liverpool L7 8XP
Date

Dear *Name*

RE: How well do patients die? Assessing relatives' views regarding the quality of care for dying patients.

Study by Dr Catriona Mayland, Dr EMI Williams and Professor JE Ellershaw from the Marie Curie Palliative Care Institute, Liverpool

The above project, led by Professor Ellershaw, is looking at the quality of care received by people in their last days of life and the experiences of their family and friends during this time. It is very important to know about the experiences of people at this difficult time. The information you provide will help to plan better end-of-life care in the future. We have enclosed an information sheet to give you further details of the study.

We would like to invite you to help with this study and would be grateful if you would complete and return the enclosed questionnaire in the pre-paid reply envelope. All information will be treated confidentially.

We appreciate the questionnaire may bring back strong memories and emotions. If you would like additional support, please feel free to ring the Psychological and Social Support Team at the Marie Curie Hospice on the following number: 0151 801 1480/1456. Alternatively, you can contact the principle co-investigator, Dr Catriona Mayland, who is based within the Palliative Care Team at the Royal Liverpool Hospital, on 0151 706 2274.

If you are unable to answer the questionnaire, for any reason, we would be grateful if you would pass it on to whoever may be the best person to take part. Alternatively, please return the response form to us so that we do not contact you again.

If you do not wish to take part in this study please complete the response form and return it in the pre-paid reply envelope. This will ensure that you do not receive any reminder letters from us.

Thank you for reading this information.

Yours sincerely

Dr Catriona Mayland
Clinical Research Fellow in Palliative Medicine

Appendix 12: PARTICIPANT INFORMATION SHEET (main study)

How well do we care for dying patients? Assessing relatives' views about the quality of care at the end-of-life.

Contact for Further Information:

**Dr Catriona Mayland, Clinical Research Fellow in Palliative Medicine
Marie Curie Palliative Care Institute, Directorate of Palliative Care, Royal
Liverpool Hospital, Liverpool.
Tel: 0151 706 2274 Email: catriona.mayland@rlbuht.nhs.uk**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

The purpose of this study is to look at the quality of care and support provided to patients in their last days of life, and the experiences of their families and friends during this time. We wish to compare the care of patients in a hospice and a hospital setting. The information that you provide will be used to help improve services in the future.

Why have I been chosen?

You have been asked to participate in this study because the clinical records indicate you are next-of-kin to a patient who died of cancer in the Royal Liverpool Hospital or the Marie Curie Hospice, Liverpool. Other people, who were family members or close friends, to patients who died in these places will also be invited to participate in this research (approximately 500 people).

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. Participation is voluntary and you may change your mind or choose not to continue in the study at any time, without having to give a reason for doing so.

What will happen to me if I take part?

You will be invited to complete the enclosed questionnaire that will take about an hour to complete. This questionnaire has been tested for its suitability of use.

What do I have to do?

To take part in this study, you will be asked to complete the enclosed questionnaire and return it using the pre-paid envelope provided. The questionnaire contains a series of questions relating to the care and experiences that you and your family member or friend received in their last two days of life.

We would also like you to indicate on the response form whether you are prepared to complete the same questionnaire again in approximately four weeks time. If you indicate you would be willing to do this, the questionnaire will be sent out again.

However, if you decide not to complete the questionnaire, please return the response form using the pre-paid envelope provided so that the research team do not contact you again.

What is the drug or procedure that is being tested?

We are looking at see whether the care received by patients dying from cancer varies between the hospice and hospital setting. More so, we are looking to see what specific aspects of care are different to help provide guidance regarding areas to improve in the future.

What are the possible disadvantages and risks of taking part?

We appreciate this is a sensitive area and it is possible that you may find some of the questions upsetting. If this is the case, you do not need to continue completing the questionnaire and you can stop at any time. The Psychological and Social Care Team at the Marie Curie Hospice, Liverpool can provide additional support if needed. Christine Sutcliffe, Principle Social Worker, can be contacted directly on 0151 801 1480.

What are the possible benefits of taking part?

There may be no direct benefits for you from taking part in this study. However, some people find it useful to have the opportunity to give feedback about the care their family member or friend received. On a wider perspective, the benefits of taking part will help highlight the areas of care that need to be improved as regards care of dying patients.

What if something goes wrong?

The Liverpool Ethics Committee has reviewed the study and it is unlikely that you will be harmed in any way. However, in the event that some harm may befall you, there are no special compensation arrangements for this study. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this,

if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service and Marie Curie Hospice complaints mechanisms would be available to you.

If you have concerns about any aspect of this study, then please ask.

Will my taking part in this study be kept confidential?

All information that is collected about you and your family member or friend during the course of the research will be kept strictly confidential. Each questionnaire has a unique identity number and does not contain details of your name or address. This ensures that the information you provide is totally anonymous. The information shall be carefully stored until the completion of the project, estimated to be 2011.

Although we do not have details of your individual General Practitioner and Consultant, all GPs in the Cheshire and Merseyside region, the Medical Director at Royal Liverpool Hospital and the Consultants at the Marie Curie Hospice, Liverpool are aware of this research project.

What will happen to the results of the research study?

The results from the study will be written up and presented at appropriate professional conferences and a report for the Marie Curie Palliative Care Institute will be published. If you would like to receive a copy of this report, this can be arranged.

Who is organising and funding the research?

The research project has been organised by the Marie Curie Palliative Care Institute. The principle co-investigator is Dr Catriona Mayland and she will take overall responsibility for the security and confidentiality of the information given in the questionnaire. Marie Curie Cancer Care has provided funding for the project.

If you agree to participate in this study you will be given a copy of the information sheet to keep.

Thank you for taking the time to read this information sheet.

Appendix 13: Response form (main study)

Please delete as appropriate:

- 1. I do wish to participate in this project and have enclosed my completed questionnaire.

- 2. I do not wish to participate in this project.

If you would like to, please comment on your reasons for not participating.

Please return this response form in the freepost envelope enclosed.
Thank you.

Appendix 14: Overall evaluation of individual question items from ECHO-D questionnaire
Section A – Overall evaluation of validity and reliability for individual question items

Question	Face validity	Content validity	Variability <0.1 = poor >0.9	Missing responses poor = >10% missing	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
A1a whether given info. on family room/quiet area	Satisfactory	LCP goal 8 (family given hospital info) but not key 'quality' indicator	Satisfactory	Satisfactory	Good stability	Not assessed	Not assessed	Provide useful intro. to ECHO-D	Revision – single question would suffice
A1b quality of family room/quiet area	Satisfactory	LCP focuses on providing info. rather than quality	Satisfactory	Poor (n=62)	Poor – may be related to missing responses	One factor solution – part of FACILITIES scale	Cronbach's alpha 0.92 - need to retest for item redundancy	Provide useful intro. to ECHO-D	Revision - change layout to try to reduce missing responses
A2a whether given info. on car parking	May not have received info. but still used facilities	LCP goal 8 (family given hospital info) but not key 'quality' indicator	Satisfactory	Poor (n=28)	Moderate stability	Not assessed	Not assessed	Provide useful intro. to ECHO-D	Revision – single question would suffice
A2b quality of car parking	Satisfactory	LCP focuses on providing info. rather than quality	Satisfactory	Poor (n=56)	Good stability	One factor solution – part of FACILITIES scale	Cronbach's alpha 0.92 - need to retest for item redundancy	Provide useful intro. to ECHO-D	Revision - change layout to try to reduce missing responses
A3a whether given info. on sleeping facilities	Satisfactory	LCP goal 8 (family given hospital info) - not key 'quality' indicator	Satisfactory	Satisfactory	Moderate stability	Not assessed	Not assessed	Provide useful intro. to ECHO-D	Revision – single question would suffice

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
A3b quality of sleeping facilities	Satisfactory	LCP focuses on providing info. rather than quality	Satisfactory	Poor (n=92)	Good stability	One factor solution – part of FACILITIES scale	Cronbach's alpha 0.92 - need to retest for item redundancy	Provide useful intro. to ECHO-D	Revision - change layout to try to reduce missing responses
A4a whether given info. on washroom/toilet	Satisfactory	LCP goal 8 (family given hospital info) but not key 'quality' indicator	Satisfactory	Satisfactory	Good stability	Not assessed	Not assessed	Provide useful intro. to ECHO-D	Revision – single question would suffice
A4b quality of washroom/toilet	Satisfactory	LCP focuses on providing info. rather than quality	Satisfactory	Poor (n=78)	Moderate stability	One factor solution – part of FACILITIES scale	Cronbach's alpha 0.92 - need to retest for item redundancy	Provide useful intro. to ECHO-D	Revision - change layout to try to reduce missing responses
A5a whether given info. on food	May have used facilities but not have received info.	LCP goal 8 (family given hospital info) but not key 'quality' indicator	Satisfactory	Satisfactory	Good stability	Not assessed	Not assessed	Provide useful intro. to ECHO-D	Revision – single question would suffice
A5b quality of food	Lack of clarity whether patients or relatives food	LCP focuses on providing info. rather than quality	Satisfactory	Poor (n=83)	Moderate stability	One factor solution – part of FACILITIES scale	Cronbach's alpha 0.92 - need to retest for item redundancy	Provide useful intro. to ECHO-D	Revision – clarify & change layout to try to reduce missing responses
A6a whether given info. on drinks	Satisfactory	LCP goal 8 (family given hospital info) but not key 'quality' indicator	Satisfactory	Satisfactory	Moderate stability	Not assessed	Not assessed	Provide useful intro. to ECHO-D	Revision – single question would suffice

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
A6b quality of drinks	Satisfactory	LCP focuses on providing info. rather than quality	Poor (‘poor’=7.4%)	Poor (n=65)	Poor – may be related to missing responses	One factor – part of FACILITIES scale	Cronbach’s alpha 0.92 - need to retest for item redundancy	Provide useful intro. to ECHO-D	Revision - change layout to try to reduce missing responses
A7 convenience of visiting hours	Satisfactory	LCP goal 8 but not key ‘quality’ indicator	Poor (‘no’=8.0%)	Satisfactory	Moderate (high % agreement & low Kappa - skewed distribution)	Not assessed	Not assessed	Provide useful intro. to ECHO-D	Retain unaltered

Section B – Overall evaluation of validity and reliability for individual question items

Question	Face validity	Content validity	Variability <0.1 = poor >0.9	Missing responses poor = >10% missing	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
B1 whether personal care needs were met	Satisfactory – understood term 'personal care needs'	LCP goal (comfortable & safe) & key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Moderate stability	One factor solution – part of CARE scale	Cronbach's alpha 0.93 – may need to retest for item redundancy	Clinically important	KEY QUESTION
B2 whether nursing care needs were met	Satisfactory	LCP goal (comfortable & safe) & key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Moderate stability	One factor solution – part of CARE scale	Cronbach's alpha 0.93 – may need to retest for item redundancy	Clinically important	KEY QUESTION
B3 comfortable environment	Satisfactory	Relates to LCP goal (needs of family accommodated) & key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Moderate stability	One factor solution – part of WARD ENVIRONMENT scale	Cronbach's alpha 0.78 - satisfactory	Clinically important	KEY QUESTION
B4 private environment	Satisfactory	Relates to LCP goal (needs of family accommodated) & key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Moderate stability	One factor solution – part of WARD ENVIRONMENT scale	Cronbach's alpha 0.78 - satisfactory	Clinically important	KEY QUESTION
B5 noise level of ward area	Satisfactory	Relates to LCP goal (needs of family accommodated)	Poor ('too quiet'=2.7%)	Satisfactory	Good stability	Not assessed	Not assessed	Provides additional info. about ward area	Retain unaltered

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
B6 cleanliness of ward area	Satisfactory	Relates to LCP goal & key quality indicator	Skewed distribution but discriminates between hospice/hospital ('not at all clean'=8.2%) Satisfactory	Satisfactory	Good stability	One factor solution – part of WARD ENVIRONMENT scale	Cronbach's alpha 0.78 - satisfactory	Provides additional info. about ward area	KEY QUESTION
B7 method of giving fluids	Satisfactory – understood terms used for mouth care	Relates to LCP goal 3 (discontinue inappropriate interventions)	Satisfactory	Satisfactory	Moderate stability	Not assessed	Not assessed	Provides context for questions on fluids	Retain unaltered
B8 whether method of giving fluids appropriate	Difficulty making judgement – often 'don't know'	Relates to LCP goal 3 (discontinue inappropriate interventions)	Majority answer 'yes' or 'don't know'	Satisfactory	Poor – due to difficulty making judgement	Not assessed	Not assessed	Provides context for questions on fluids	Retain unaltered
B9 whether discussion occurred about 'drip' B9b would discussion have been helpful	Satisfactory – emotive but deemed very important	Discussion not specified in LCP goal 3 (discontinue inappropriate interventions)	Satisfactory	Poor for stem part of question (n=32)	Moderate stability	Formed composite variable HYDRATION INFO. NEEDS	Not assessed	Clinically important	KEY QUESTION – revise layout for stem question to reduce missing responses
B10 unnecessary checks/tests	Difficulty making judgement – often 'don't know'	LCP goals 3 & 3a (discontinue inappropriate interventions & nursing interventions)	Satisfactory	Satisfactory	Moderate stability	Not assessed	Not assessed	No specific factors	Retain unaltered

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
B11 confidence & trust in nurses	Double question but acceptable	Key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Good stability	One factor solution – part of CARE scale	Cronbach's alpha 0.93 - need to retest for item redundancy (overlap with B13)	Clinically important	KEY QUESTION
B12 confidence & trust in doctors	Double question but acceptable; spelling error	Key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Good stability	One factor solution – part of CARE scale	Cronbach's alpha 0.93 - need to retest for item redundancy (overlap with B14)	Clinically important	KEY QUESTION Correct spelling error
B13 overall nursing care	Participants recalled care prior to last 2 days	Key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Moderate stability	One factor solution – part of CARE scale	Cronbach's alpha 0.93 - need to retest for item redundancy (overlap with B11)	Clinically important	Retain unaltered - but may be redundant due to overlap with other questions
B14 overall medical care	Participants recalled care prior to last 2 days	Key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Moderate stability	One factor solution – part of CARE scale	Cronbach's alpha 0.93 - need to retest for item redundancy (overlap with B12)	Clinically important	Retain unaltered - but may be redundant due to overlap with other questions

Section C – Overall evaluation of validity and reliability for individual question items

Question	Face validity	Content validity	Variability <0.1 = poor >0.9	Missing responses poor = >10% missing	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
C1 unconscious or drowsy	Emotive; may need further clarity in response options	Setting context but not key quality indicator	Satisfactory	Satisfactory	Moderate stability	Not assessed	Not assessed	Provides context for other questions in section	Retain unaltered
C2a continue talking and interacting	Uncertainty about term 'interacting'	Not key quality indicator	Poor (‘no’ =7.5%)	Satisfactory	Moderate stability	Not assessed	Not assessed	No specific factors	Omission – lacks clarity
C2b staff support to do this	Lacks clarity	Links with LCP goal (patient aware of situation) - not key ‘quality’ indicator	Satisfactory	Poor (n=27)	Moderate stability	Not assessed	Not assessed	No specific factors	Revision – revise wording and layout
C3 appear in pain	Satisfactory; Emotive but deemed very important	LCP goal (pain free) and key ‘quality’ indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Moderate stability	Formed composite variable – SYMPTOM BURDEN	Not assessed	Clinically important	KEY QUESTION despite issues of using proxy’s to assess pain
C4 severity of pain	Difficulty making judgement – often ‘don’t know’	LCP goal (pain free) and key ‘quality’ indicator	Satisfactory	Satisfactory	Poor – may reflect difficulty making judgement	Not assessed	Not assessed	Clinically important	Retain unaltered – reflects limitations in proxy assessment

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
C5 did staff do enough to control pain	Satisfactory	LCP goal (pain free) and key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Poor – may reflect difficulty making judgement	Formed composite variable – SYMPTOM CONTROL	Not assessed	Clinically important	KEY QUESTION despite issues of using proxy's to assess pain
C6 appear restless	Satisfactory – understood term	LCP goal (not agitated) and key 'quality' indicator	Satisfactory	Satisfactory	Moderate stability	Formed composite variable – SYMPTOM BURDEN	Not assessed	Clinically important	KEY QUESTION
C7 staff should have done more for restlessness	Satisfactory	LCP goal (not agitated) and key 'quality' indicator	Satisfactory	Satisfactory	Moderate stability	Formed composite variable – SYMPTOM CONTROL	Not assessed	Clinically important	KEY QUESTION Revise response options - in keeping with pain question C5
C8 have 'noisy rattle' to breathing	Satisfactory – understood term	LCP goal (no excessive secretions) and key 'quality' indicator	Satisfactory	Satisfactory	Good stability	Formed composite variable – SYMPTOM BURDEN	Not assessed	Clinically important	KEY QUESTION
C9 was 'noisy rattle' distressing	Satisfactory - unrecognised info. needs regarding reason for symptom	Relates to LCP goal (family preparation) but not specifically stated)	Satisfactory	Satisfactory	Good stability	Not assessed	Not assessed	Clinically important	Revision – asking about why symptom arises may be more important

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
C10 staff should have done more for 'noisy rattle'	Satisfactory	LCP goal (no excessive secretions) and key 'quality' indicator	Satisfactory	Poor (n=27)	Good stability	Formed composite variable – SYMPTOM CONTROL	Not assessed	Clinically important	KEY QUESTION Revise response options in keeping with question C5
C11 have nausea /vomiting	Satisfactory	LCP goal (no nausea/vomits) and key 'quality' indicator	Poor – relates to lower prevalence of symptom ('yes, all of the time'=3.6%)	Satisfactory	Moderate (high % agreement & low Kappa - skewed distribution)	Formed composite variable – SYMPTOM BURDEN	Not assessed	Clinically important	Retain unaltered
C12 staff should have done more for nausea/vomit ing	Satisfactory	LCP goal (no nausea/vomits) and key 'quality' indicator	Poor – relates to lower prevalence of symptom ('yes'=6.7%)	Satisfactory	Moderate (high % agreement & low Kappa - skewed distribution)	Formed composite variable – SYMPTOM CONTROL	Not assessed	Clinically important	Revision – revise response options in keeping with question C5
C13 appear breathless	Satisfactory	LCP goal (no dyspnoea) and key 'quality' indicator	Satisfactory but less prevalent than pain, RTS and restlessness	Satisfactory	Moderate stability	Formed composite variable – SYMPTOM BURDEN	Not assessed	Clinically important	Retain unaltered
C14 staff should have done more for shortness of breath	Satisfactory	LCP goal (no dyspnoea) and key 'quality' indicator	Satisfactory but less prevalent than pain, RTS and restlessness	Poor (n=27)	Good stability	Formed composite variable – SYMPTOM CONTROL	Not assessed	Clinically important	Revision - revise response options in keeping with question C5

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
C15 staff should have done more to keep mouth clean	Satisfactory	LCP goal (mouth is moist & clean)	High numbers of 'don't knows'	Satisfactory	Poor	Not assessed	Not assessed	Clinically important	Revise response options in keeping with question C5

Section D – Overall evaluation of validity and reliability for individual question items

Question	Face validity	Content validity	Variability <0.1 = poor >0.9	Missing responses poor = >10% missing	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
D1 whether staff asked about patients beliefs	May not know information or have difficulty with recall	LCP goal 6 (religious/spiritual needs assessed) & key 'quality' indicator	Satisfactory	Satisfactory	Poor – related to recall difficulties	Formed composite scale – SPIRITUAL NEEDS (P)	Not assessed	No specific factors	Retain unaltered
D2 whether staff asked about relatives beliefs	Satisfactory	LCP goal 6 (religious/spiritual needs assessed) & key 'quality' indicator	Satisfactory	Satisfactory	Moderate stability	Formed composite scale – SPIRITUAL NEEDS (R)	Not assessed	No specific factors	Retain unaltered
D3 support to patient from religious leader	May not apply if patient not religious	LCP goal 6 (religious/spiritual needs assessed) & key 'quality' indicator	Satisfactory	Satisfactory	Moderate stability	Formed composite scale – SPIRITUAL NEEDS (P)	Not assessed	No specific factors	Retain unaltered
D4 support to relative from religious leader	Satisfactory	LCP goal 6 (religious/spiritual needs assessed) & key 'quality' indicator	Satisfactory	Satisfactory	Good stability	Formed composite scale – SPIRITUAL NEEDS (R)	Not assessed	No specific factors	Retain unaltered
D5 whether asked about important rituals at time of death	Satisfactory	LCP goal 6 (religious/spiritual needs assessed) & key 'quality' indicator	Satisfactory	Satisfactory	Moderate stability	Formed composite scale – SPIRITUAL NEEDS (P)	Not assessed	No specific factors	Retain unaltered

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
D6 patients overall spiritual needs met	Could find multiple response options difficult	LCP goal 6 (religious/spiritual needs assessed) & key 'quality' indicator	Satisfactory - <10% 'strongly disagree' but normal distribution	Satisfactory	Good stability	Formed composite scale – SPIRITUAL NEEDS (P)	Not assessed	No specific factors	KEY QUESTION
D7 relatives overall spiritual needs met	Satisfactory	LCP goal 6 (religious/spiritual needs assessed) & key 'quality' indicator	Satisfactory	Satisfactory	Moderate stability	Formed composite scale – SPIRITUAL NEEDS (R)	Not assessed	No specific factors	KEY QUESTION

Section E – Overall evaluation of validity and reliability for individual question items

Question	Face validity	Content validity	Variability <0.1 = poor >0.9	Missing responses poor = >10% missing	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
E1 whether participants knew how to contact hospice/hospital	Satisfactory	Links with LCP goal 7 (identify how to inform family of death) but limited additional info.	Satisfactory although skewed distribution with most responses 'yes'	Satisfactory	Satisfactory (high % agreement & low Kappa - skewed distribution)	Not assessed	Not assessed	No specific factors	Omission – only provides limited info.
E2 whether hospice/hospital knew how to contact participants in emergency	Satisfactory	LCP goal 7 (identify how to inform family of death) but not key 'quality' indicator	Poor ('no'=2%)	Satisfactory	Satisfactory (high % agreement & low Kappa - skewed distribution)	Not assessed	Not assessed	No specific factors	Omission - only provides limited info.
E3 involvement in decision-making	Satisfactory	LCP goal 10 (plan of care discussed) & key 'quality' indicator	Satisfactory	Satisfactory	Moderate stability	One factor solution - part of COMMUNICATION scale	Cronbach's alpha 0.73 - satisfactory	Clinically important	KEY QUESTION
E4 involved in decisions as much as wanted	Satisfactory	LCP goal 10 (plan of care discussed) & key 'quality' indicator	Satisfactory	Satisfactory	Poor – difficulty making judgement	Not assessed	Not assessed	Provides additional info. for question 3	Retain unaltered
E5 decision made that didn't want	Satisfactory	LCP goal 10 (plan of care discussed) & key 'quality' indicator	Satisfactory	Satisfactory	Good stability	Not assessed	Not assessed	Clinically important	Retain unaltered

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
E6 quality of explanations	Satisfactory	LCP goal 11 (family understand plan of care) & key 'quality' indicator	Poor – skewed distribution but discriminates between hospice/hospital	Satisfactory	Moderate stability	One factor solution - part of COMMUNICATION scale	Cronbach's alpha 0.73 - satisfactory	Clinically important	KEY QUESTION Correct spelling mistake
E7 checking understanding	Satisfactory	Relates to LCP goal 11 (family understand plan of care)	Satisfactory	Satisfactory	Moderate stability	Not assessed	Not assessed	Some overlap with question E6	Retain unaltered
E8 offer of translator	Not relevant to many participants	LCP goal 4 (ability to communicate in English) but not key 'quality' indicator	Poor 'yes'=1.6% may relate to sample population	Satisfactory	Moderate (high % agreement & low Kappa - skewed distribution)	Not assessed	Not assessed	Important - only relevant to small proportion of our sample	Retain unaltered
E9 unresolved emotional issues	Concerns about clarity	Not key 'quality' indicator	Poor 'yes'=9% Also high number 'not sure'	Satisfactory	Moderate stability	Not assessed	Not assessed	No specific factors	Omission – lacks clarity
E10 discuss worries and fears	Satisfactory	LCP goal 11 (family understand plan of care) but not key 'quality' indicator	Satisfactory	Satisfactory	Good stability	Not assessed	Not assessed	No specific factors	Retain unaltered

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
E11a discuss concerns for children E11b would discussion have been helpful	Satisfactory	Relates to LCP goal (needs of family are accommodated) but not key 'quality' indicator	Satisfactory	Satisfactory	Good stability (except for stem part of question – poor)	Not assessed	Not assessed	Clinically important	Retain unaltered
E12 conflicting information	Satisfactory	Key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Moderate stability	Not assessed	Not assessed	No specific factors	Retain unaltered
E13 with holding information	Satisfactory	Key 'quality' indicator	Skewed distribution and doesn't discriminate hospice/hospital care	Satisfactory	Moderate stability	Not assessed	Not assessed	Provides continuity for questions about info.	Retain unaltered
E14 doctors had time to listen	Satisfactory	Relates to LCP goal (family prepared for death) & key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Good stability	One factor solution - part of COMMUNICATION scale	Cronbach's alpha 0.73 - satisfactory	Clinically important	KEY QUESTION
E15 nurses had time to listen	Satisfactory	Relates to LCP goal (family prepared for death) & key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Moderate stability	One factor solution - part of COMMUNICATION scale	Cronbach's alpha 0.73 - satisfactory	Clinically important	KEY QUESTION

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
E16 overall emotional support	Satisfactory	Relates to LCP goal (needs family accommodated) & key 'quality' indicator	Satisfactory	Satisfactory	Moderate stability	One factor solution – part of CARE scale	Cronbach's alpha 0.93 - need to retest for item redundancy	Clinically important	KEY QUESTION

Section F – Overall evaluation of validity and reliability for individual question items

Question	Face validity	Content validity	Variability <0.1 = poor >0.9	Missing responses poor = >10% missing	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
F1 told likely to die	Emotive but important question; discussion could occur prior to last 2 days	LCP goal 5 (insight into condition) & key 'quality' indicator	Satisfactory	Satisfactory	Good stability	68.4% participants who had this conversation answered they were adequately supported (question G5)	Not assessed	Clinically important	KEY QUESTION
F2 chance to talk about dying	Satisfactory	LCP goal (family prepared)	Satisfactory	Satisfactory	Moderate stability	Not assessed	Not assessed	Provides additional info. for question F1	Retain unaltered
F3 first time aware dying	Satisfactory	LCP goal (family prepared)	Satisfactory	Satisfactory	Good stability	Not assessed	Not assessed	Provides additional info. for question F1	Retain unaltered
F4 privacy when told	Satisfactory	LCP goal (family prepared)	Poor 'no'=7.6%	Satisfactory	Good stability	Not assessed	Not assessed	Provides additional info. for question F1	Retain unaltered
F5 told sensitively	Satisfactory	LCP goal (family prepared)	Poor 'no'=2.7%	Satisfactory	Good stability	Not assessed	Not assessed	Provides additional info. for question F1	Retain unaltered

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
F6a written info. about dying F6b info. easy to understand F6c info. would have been useful	Satisfactory	LCP goal (family prepared for death) but not key 'quality' indicator	Satisfactory except stem F6b 'no'=3.1%	Satisfactory except stem F6c (n=41)	Moderate stability	Formed composite variable – UNMET NEED – WRITTEN INFO. ABOUT DYING	Not assessed	No specific factors	Revision – consider omitting stem F6b
F7a discussion about dying F7b discussion would have been useful	Satisfactory	LCP goal (family prepared for death) and key 'quality' indicator	Satisfactory	Satisfactory	Good stability	Formed composite variable – UNMET NEED – DISCUSSION ABOUT DYING	Not assessed	Relatives deemed very important	KEY QUESTION
F8a preference for place of death F8b discussed with healthcare team	Satisfactory	Key quality indicator	Satisfactory except stem F8b 'no'=9%	Satisfactory	Good stability except stem F8b (moderate)	Not assessed	Not assessed	Sets context for following questions	Retain unaltered
F9 place of death	Satisfactory	Key quality indicator	Satisfactory	Satisfactory	Good stability	Not assessed	Not assessed	For this sample already knew place of death	Retain unaltered
F10 died in right place	Satisfactory	Key quality indicator	Satisfactory although 9.4% 'not sure'	Satisfactory	Poor – related to difficulty making judgements	Not assessed	Not assessed	Clinically important	KEY QUESTION – due to importance of issue

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
F11 asked if wanted to be present when died	Satisfactory	LCP goal 7 (identify how to inform family of death) & key 'quality' indicator	Satisfactory	Satisfactory	Good stability	Not assessed	Not assessed	No specific factors	Retain unaltered
F12 with patient when died	Emotive question if participant not with patient when died	Links with LCP goal 7 (identify how to inform family of death)	Satisfactory	Satisfactory	Good stability	Not assessed	Not assessed	No specific factors	Retain unaltered
F13 support at time of death	Difficulty with recall	Links with LCP goal 14 (procedure following death carried out) & key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Moderate stability	One factor solution – part of CARE scale	Cronbach's alpha 0.93 - need to retest for item redundancy	Clinically important	KEY QUESTION
F14 return of personal belongings	Difficulty with recall; sometimes not applicable	LCP goal 16 (hospital policy for patient's belongings)	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Good stability	Not assessed	Not assessed	No specific factors	Retain unaltered
F15 rituals at time of death	Satisfactory	LCP goal 14 (procedure following death carried out)	Almost half answered 'not applicable' (47.5%)	Satisfactory	Moderate stability	Not assessed	Not assessed	No specific factors	Retain unaltered – consider omission (often N/A)

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
F16a info. about registering death F16b was it useful	Difficulty with recall	LCP goal 15 (family given info. on procedures) & 17 (documentation given to family)	Poor 'no'=8.2% and almost everyone found it useful	Satisfactory except stem part of question (n=48)	Poor for first part of question – has negative Kappa	Not assessed	Not assessed	No specific factors	Retain unaltered – consider omitting stem part of question
F17a info. about bereavement F17b was it useful	Difficulty with recall	LCP goal 18 (bereavement leaflet given)	Satisfactory except stem question 'no'=5.9%	Satisfactory except stem part of question (n=32)	Moderate stability	Not assessed	Not assessed	No specific factors	Retain unaltered – consider omitting stem part of question
F18a talk with bereavement service F18b was it useful	Satisfactory	Relates to LCP goal 18 (bereavement leaflet given)	Satisfactory except stem question 'no'=0.4%; high percent 'not applicable' (85.9%)	Satisfactory	Good stability	Not assessed	Not assessed	No specific factors	Revision – ask whether would like to have talked to someone
F19 dealt with sensitive manner	Satisfactory	Relates to LCP goal 18 (bereavement leaflet given)	Poor 'no' =5.9%; high percent 'not applicable' (60.4%)	Satisfactory	Moderate stability	Not assessed	Not assessed	Clinically important	KEY QUESTION – revision required so relevant to more participant; change time focus

F20 lack of communication about death	Lacks clarity	Relates to LCP goal 12 (GP contacted re death) and 13 (procedures for laying out)	Satisfactory	Satisfactory	Moderate stability	Not assessed	Not assessed	No specific factors	Revision – ask specifically ask about contact with GP
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Section G – Overall evaluation of validity and reliability for individual question items

Question	Face validity	Content validity	Variability	Missing responses	Test-retest reliability	Construct validity	Internal consistency	Other factors	Overall conclusion
G1 respect and dignity	Satisfactory	Fundamental aim of LCP & key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Good stability	Higher CARE & WARD ENVIRONMENT scores – predict being treated with dignity & respect	Not assessed	Fundamental importance	KEY QUESTION
G2 treated as individual	Satisfactory – understood term	Fundamental aim of LCP & key 'quality' indicator	Skewed distribution but discriminates between hospice/hospital	Satisfactory	Moderate stability	Not assessed	Not assessed	No specific factors	Retain unaltered
G3 at peace	Difficulty making judgement	Key 'quality' indicator	Satisfactory but high percent 'don't know' (18.0%)	Satisfactory	Moderate stability	Not assessed	Not assessed	No specific factors	Retain unaltered
G4 dignified death	Challenged whether dignified death ever possible	Key 'quality' indicator	Poor 'no'=9.8%	Satisfactory	Good stability	Not assessed	Not assessed	No specific factors	Omission - could duplicate aspects of G1
G5 adequate support of family	Satisfactory	Fundamental aim of LCP & key 'quality' indicator	Satisfactory	Satisfactory	Moderate stability	Higher CARE & COMMUNICATION scores – predict being treated with dignity & respect	Not assessed	Fundamental importance	KEY QUESTION

Appendix 15: Version 2 of ECHO-D

ECHO-D

Evaluating Care & Health Outcomes for the Dying

- This is a questionnaire on the care received by people in the last hours and days of life and the experiences of their families and friends during that time.
- The team at the Marie Curie Palliative Care Institute consider the care of dying patients to be a priority. We also think it is important to find out more about the care and support you, your family and friends received at the time of death. Your views are, therefore, important to us. Please fill in as much of the questionnaire as you can.
- We realise this questionnaire may bring back strong memories and emotions and that reading it for the first time may be difficult. You may wish to wait and find someplace quiet to read the questionnaire. If you feel upset or distressed in any way, you do not have to continue with the questionnaire and can stop at any time. However, if you wish to, you can return to the questionnaire at a future time.

**Your answers will, of course, be treated as strictly confidential.
Individuals will not be identifiable in the reports we write.**

- You have been sent this questionnaire as you are registered as the next of kin to a patient who died in the Royal Liverpool & Broadgreen University Hospitals or the Marie Curie Hospice, Liverpool. However, if you feel unable to answer the questionnaire, for any reason, you can pass it on to someone else who may be better placed to complete it.
- Although we know the patient's name, for convention, we have referred to them as 's/he' in the questionnaire.

The Marie Curie Palliative Care Institute, Liverpool

- This is a partnership between the Marie Curie Hospice, Liverpool, the Royal Liverpool and Broadgreen University Hospital NHS Trust and the University of Liverpool. The key aim of the Institute is to improve the care of dying patients through research, development and education.

Content of Questionnaire

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Instructions for completion

- As you go through the questionnaire, please follow the instructions and answer the questions by crossing the most appropriate box, like this: [×]
- Here is an example question:

B11. In your view, did s/he have any unnecessary tests or checks (for example too many blood tests or blood pressure checks)?

Yes	<input checked="" type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>

If, in your opinion, your family member or friend had unnecessary tests or checks, you would cross the 'Yes' box as in the example.

- If you would rather not or cannot answer one of the questions, please go onto the next one.
- We are very interested in what you have to say. Please continue on extra sheets if necessary.

We know s/he was cared for either at the Royal Liverpool Hospital or the Marie Curie Hospice in the days before s/he died. The questions are related to the last hours and days of his/her life, the care s/he received and your experience of that time. We would like you to reflect on this period. In particular, we would like you to focus on the last **two days** of his/her life, when answering these questions.

Section A: The available facilities

These questions are concerned with the facilities that were available for you, your family members and friends in the hospital or hospice during the last **two days** of his/her life.

A1. Were you, your family members or friends given information (either verbally or written) about the availability of the hospice/hospital facilities such as car parking, and overnight accommodation?

- Yes☐
- No☐
- Don't know☐

A2. How would you rate the quality of the following facilities?

- a. A family room or quiet area

Poor☐

Fair☐

Good☐

Excellent☐

Don't know☐
- b. Car parking facilities

Poor☐

Fair☐

Good☐

Excellent☐

Don't know☐
- c. Sleeping facilities

Poor☐

Fair☐

Good☐

Excellent☐

Don't know☐
- d. Washroom and toilet facilities

Poor☐

Fair☐

Good☐

Excellent☐

Don't know☐
- e. Food available for you

Poor☐

Fair☐

Good☐

Excellent☐

Don't know☐

- e. Drinks available for you

Poor

Fair

Good

Excellent

Don't know

☐

☐

☐

☐

☐

A7. Did you find the visiting hours convenient?

- Yes

No
- ☐

☐

Please feel free to comment, if you wish to, on any aspect of the facilities that were provided to you, your family members and friends:

Section B: The care received from the nurses and doctors

These questions are concerned with the general care s/he received from the doctors and nurses and the environment in which this care was delivered. The questions apply to the last two days of his/her life.

Please look at the following statements and tick the answer box that corresponds most with your opinion.

B1. There was enough help available to meet his/her personal care needs, such as washing, personal hygiene and toileting needs.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

B2. There was enough help with nursing care, such as giving medicines and helping him/her find a comfortable position in bed.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

B3. The bed area and surrounding environment was comfortable for him/her.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

B4. The bed area and surrounding environment had adequate privacy for him/her.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

B5. During his/her last two days, in your view, how did you find the general noise level of the ward?

- Too noisy ☐
- About right ☐
- Too quiet ☐

B6. In your opinion, how clean was the ward area that s/he was in?

- Very clean ☐
- Fairly clean ☐
- Not at all clean ☐

B7. How were fluids given to him/her in the last two days of his/her life?

- By moistening his/her mouth with a damp sponge ☐
- By giving sips of water ☐
- By giving fluids through a 'drip' ☐
- No fluids were given ☐
- Don't know ☐
- Other (please specify) _____

B8. In your opinion, was this way of providing fluids the appropriate one?

- Yes ☐
- No ☐
- Don't know ☐

Please feel free to comment if you wish to: _____

B9. Did any of the doctors or nurses discuss with you whether giving fluids through a 'drip' would be appropriate in the last two days of life?

- Yes ☐
- No ☐
- Don't know ☐

B10. Would a discussion about the appropriateness of giving fluids through a 'drip' in the last two days of life have been helpful?

- Yes ☐
- No ☐
- Not applicable, we had these types of discussions ☐

B11. In your view, did s/he have any unnecessary tests or checks (for example too many blood tests or blood pressure checks)?

- Yes ☐
- No ☐
- Don't know ☐

B12. Did you have confidence and trust in the nurses who were caring for him/her?

- Yes, in all of them ☐
- Yes, in some of them ☐
- No, not in any of the nurses ☐

B13. Did you have confidence and trust in the doctors who were caring for him/her?

- Yes, in all of them ☐
- Yes, in some of them ☐
- No, not in any of the doctors ☐

B14. Overall, how would you assess the care s/he received from the nurses?

- Excellent ☐
- Good ☐
- Fair ☐
- Poor ☐

B15. Overall, how would you assess the care s/he received from the doctors?

- Excellent ☐
- Good ☐
- Fair ☐
- Poor ☐

Please feel free to comment, if you wish to, on any aspect of the care s/he received or the environment in which this care was delivered:

Section C: The control of pain & other symptoms

These questions are concerned with the symptoms s/he had and the care s/he received during the last **two days** of his/her life.

C1. Many people are unconscious or drowsy towards the end of their life.
In his/her last two days, was s/he unconscious or drowsy?

- Yes ☐
- No ☐
- Don't know ☐

C2. Did the doctors and nurses help and support you to be with him/her (if you wanted to be), even when s/he seemed to be unconscious?

- Yes ☐
- No ☐
- Don't know ☐
- Not applicable ☐

Please feel free to comment if you wish to: _____

C3. In your opinion, during the last two days, did s/he appear to be in pain?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not appear to be in pain ☐

C4. When s/he was in pain, was it usually mild, moderate or severe?

- Mild ☐
- Moderate ☐
- Severe ☐
- Don't know ☐
- Not applicable, s/he was not in pain ☐

C5. In your view, did the doctors and nurses do enough to help relieve the pain?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, not at all ☐
- Not applicable, s/he was not in pain ☐

Please feel free to comment if you wish to: _____

C6. In your opinion, during the last two days, did s/he appear to be restless?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not appear to be restless ☐

C7. In your view, did the doctors and nurses do enough to help relieve the restlessness?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, not at all ☐
- Not applicable, s/he was not restless ☐

Please feel free to comment if you wish to: _____

C8. In your opinion, during the last two days, did s/he appear to have a ‘noisy rattle’ to his/her breathing?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not have a ‘noisy rattle’ to the breathing ☐

C9. Did you find the ‘noisy rattle’ to his/her breathing distressing?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, not at all ☐
- Not applicable, there was no ‘noisy rattle’ to his/her breathing ☐

C10. Would a discussion about why s/he had a ‘noisy rattle’ to the breathing have been helpful?

- Yes ☐
- No ☐
- Not applicable, we had these discussions with the staff ☐

C11. In your view, did the doctors and nurses do enough to help relieve the ‘noisy rattle’ to his/her breathing?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, not at all ☐
- Not applicable, there was no ‘noisy rattle’ to his/her breathing ☐

Please feel free to comment if you wish to: _____

C12. In your opinion, during these last two days, did s/he have any nausea and/or vomiting? By the term ‘nausea’, we mean ‘feeling sick’.

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not have nausea and vomiting ☐

C13. In your view, did the doctors and nurses do enough to help relieve the nausea and/or vomiting?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, not at all ☐
- Not applicable, s/he did not have nausea and/or vomiting ☐

Please feel free to comment if you wish to: _____

C14. In your opinion, during the last two days, did s/he appear breathless?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, s/he did not appear breathless ☐

C15. In your view, did the doctors and nurses do enough to help relieve the breathlessness?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, not at all ☐
- Not applicable, s/he did not appear breathless ☐

Please feel free to comment if you wish to: _____

C16. In your view, did the doctors and nurses do enough to keep his/her mouth moist and clean?

- Yes, all of the time ☐
- Yes, some of the time ☐
- No, not at all ☐
- Not applicable, his/her mouth was moist and clean ☐

Please feel free to comment, if you wish to, on any other symptoms s/he may have had and any help s/he may have received for these:

Section D: The religious and spiritual support provided by the healthcare team

The following questions are about the religious and spiritual support that was provided to you and your family member or friend by the healthcare team in the last **two days** of his/her life. By ‘**healthcare team**’, we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain.

D1. Did the healthcare team talk to him/her about their religious or spiritual beliefs?

- Yes ☐
- No ☐
- Don't know ☐

D2. Did the healthcare team talk to you about your religious or spiritual beliefs?

- Yes ☐
- No ☐

D3. Was s/he offered support from a religious or spiritual leader?

- Yes ☐
- No ☐
- Don't know ☐

D4. Were you offered support from a religious or spiritual leader?

- Yes ☐
- No ☐

D5. Did the healthcare team ask in advance about specific religious or spiritual rituals that you wanted at the time of his/her death?

- Yes ☐
- No ☐

Please look at the following statements and cross [x] the answer box that corresponds most with your opinion.

D6. Overall, his/her religious or spiritual needs were met by the healthcare team.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

D7. Overall, my religious or spiritual needs were met by the healthcare team.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

Please feel free to comment, if you wish to, on any aspect of the religious and/or spiritual support received:

Section E: Communication and emotional support

The following questions are about the communication and information that you, your family members and friends received from the healthcare team in the last **two days** of his/her life. We also want to know about the level of emotional support that was provided by the healthcare team. By **‘healthcare team’**, we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain.

E1. During the last two days, how involved were you with the decisions about his/her care and treatment?

- Very involved ☐
- Fairly involved ☐
- Not involved ☐

E2. Were you involved in decisions about his/her care and treatment as much as you wanted?

- Yes ☐
- No ☐
- Don't know ☐

E3. Was there any decision made about his/her care or treatment that you did not want?

- Yes ☐
- No ☐
- Don't know ☐

Please feel free to comment if you wish to: _____

E4. Did the healthcare team explain his/her condition and/or treatment in a way you found easy or difficult to understand?

- Very easy ☐
- Fairly easy ☐
- Fairly difficult ☐
- Very difficult ☐
- They did not explain his/her condition or treatment to me ☐

E5. Did any of the healthcare team ask about your understanding of what was happening?

- Yes ☐
- No ☐

E6. Would the offer of a translator have been useful?

- Yes ☐
- No ☐
- Not applicable ☐

E7. Were you able to discuss with the healthcare team any worries or fears you had about his/her condition and/or treatment?

- Yes ☐
- No ☐

E8. Were you given the opportunity to discuss your concerns about support for children or grandchildren (under the age of 18 years) who were most affected by his/her dying and death?

- Yes ☐
- No ☐
- Not applicable ☐

If no: Would this type of support have been useful?

- Yes ☐
- No ☐

E9. Did it ever happen that one doctor or nurses said one thing about his/her condition and treatment and another said something different?

- Yes, often ☐
- Yes, sometimes ☐
- Yes, once ☐
- No, never ☐

E10. In your opinion, did the healthcare team ever deliberately not tell you certain things you wanted to know?

- Yes, often ☐
- Yes, sometimes ☐
- Yes, once ☐
- No, never ☐

Please look at the following statements and cross [x] the answer box that corresponds most with your opinion.

E11. The doctors had time to listen and discuss his/her condition with me.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

E12. The nurses had time to listen and discuss his/her condition with me.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

E13. How would you assess the overall level of emotional support given to you by the healthcare team?

- Poor ☐
- Fair ☐
- Good ☐
- Excellent ☐

Please feel free to comment, if you wish to, on any aspect of the level of communication, information, or emotional support you, your family member or friend received:

Section F: The circumstances surrounding his/her death

The following questions are about the circumstances surrounding his/her death, and your feelings about the way in which the healthcare team treated you both at this time. By **‘healthcare team’**, we mean the doctors, the nurses and any other member of staff who may have been involved in his/her care such as a social worker or a chaplain.

F1. Before s/he died, were you told s/he was likely to die soon?

- Yes☐
- No☐

If **‘Yes’**, who told you s/he was likely to die soon? _____
Please continue with the questions below.

- **If ‘No’, please go to question F6 (on the next page)**

F2. At that time, were you given the chance to talk about the fact that s/he was dying?

- Yes☐
- No☐
- Don't know☐

F3. Was that the first time you were aware that s/he was dying?

- Yes☐
- No☐
- Don't know☐

F4. Did you have enough privacy when you were told that s/he was dying?

- Yes☐
- No☐
- Don't know☐

F5. Were you told in a sensitive manner?

- Yes☐
- No☐
- Don't know☐

Please feel free to comment if you wish to: _____

F6. Were you given any written information about what to expect when s/he was dying?

- Yes☐
- No☐

If no: Would this type of information have been useful?

- Yes☐
- No☐

Please feel free to comment if you wish to: _____

F7. Did a member of the healthcare team talk to you about what to expect when s/he was dying?

- Yes☐
- No☐

If no: Would this type of discussion have been useful?

- Yes☐
- No☐

Please feel free to comment if you wish to: _____

F8. Did s/he ever express a preference about where s/he would like to die?

- Yes (if possible, please specify place) _____
- No☐

If yes: Was this ever discussed with the healthcare team?

- Yes☐
- No☐
- Don't know☐

F9. Where did s/he die?

- Hospital☐
- Hospice☐
- Other (please specify): _____☐

F10. In your opinion did s/he die in the right place?

- Yes, it was the right place ☐
- No, it was not the right place ☐
- Not sure ☐
- Don't know ☐

If no: please tell us why it wasn't the right place

F11. Were you asked if you wanted to be present when s/he died?

- Yes ☐
- No ☐

F12. Were you with him/her when s/he died?

- Yes ☐
- No ☐

Please feel free to comment if you wish to:

Please look at the following statements and cross [x] the answer box that corresponds most with your opinion.

F13. I was given enough help and support by the healthcare team at the actual time of his/her death.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

F14. His/her personal belongings were returned to the family (or friend) in a sensitive manner.

- Strongly agree ☐
- Agree ☐
- Neither agree nor disagree ☐
- Disagree ☐
- Strongly disagree ☐

F15. Were particular practices or rituals followed after his/her death that were important to you, your family members or friends?

- Yes ☐
- No ☐
- Don't know ☐
- Not applicable ☐

Please feel free to comment if you wish to: _____

F16. After s/he had died, did you or another family member or friend receive any written information about what to do next, for example registering the death and organising the funeral?

- Yes ☐
- No ☐

If yes: Was this useful?

- Yes ☐
- No ☐

F17. Did you receive any written information about what you might experience after s/he had died (for example a bereavement or grieving leaflet)?

- Yes ☐
- No ☐

If yes: Was this useful?

- Yes ☐
- No ☐

F18. After s/he had died, did individuals from the healthcare team deal with you in a sensitive manner?

- Yes ☐
- No ☐
- Not applicable, I didn't have any contact with the healthcare team ☐

F19. Since s/he died have you talked to anyone from health or social services or from a bereavement service about your experiences regarding his/her illness and death?

- Yes☐
- No☐

If no: Would you have liked to talk to someone?

- Yes☐
- No☐
- Don't know☐

Please feel free to comment, if you wish to: _____

F20. Since s/he died, have you been in any situation in which there appeared to be a lack of communication about his/her death e.g. GP not being aware s/he had died?

- Yes☐
- No☐

Please feel free to comment if you wish to: _____

Please feel free to comment, if you wish to, on any aspect of care received around the time of his/her death and in the time since his/her death:

Section G: Overall impressions

The following questions are about your overall impression of the care s/he received in the last **two days** of life and your experiences during that time.

G1. How much of the time was s/he treated with respect and dignity by the healthcare team?

- Always ☐
- Most of the time ☐
- Some of the time ☐
- Never ☐
- Don't know ☐

G2. How much of the time was s/he treated as an individual by the healthcare team?

- Always ☐
- Most of the time ☐
- Some of the time ☐
- Never ☐
- Don't know ☐

G3. In his/her last two days, in your opinion, was s/he at peace?

- Yes ☐
- No ☐
- Don't know ☐

Please feel free to comment if you wish to: _____

G4. Overall, in your opinion, were you adequately supported during his/her last two days of life?

- Yes ☐
- No ☐

Please feel free to comment if you wish to: _____

This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Section H: Information about you

We would like to know a little more about you. This will help us make further use of the information you give us and will remain strictly confidential.

H1. What was your relationship to him/her?

Were you his/her:

- Husband / Wife / Partner ☐
- Son / Daughter ☐
- Brother / Sister ☐
- Son-in-law / Daughter-in-law ☐
- Parent ☐
- Friend ☐
- Neighbour ☐
- Staff in nursing or residential home ☐
- Warden (sheltered accommodation) ☐
- Other (please describe) ----- ☐

H2. What age group are you in?

- 18 – 19 ☐
- 20 – 29 ☐
- 30 – 39 ☐
- 40 – 49 ☐
- 50 – 59 ☐
- 60 – 69 ☐
- 70 – 79 ☐
- 80 + ☐

H3. Please could you indicate to which ethnic group you belong:

- | | | | |
|------------------------------|--------------------------|-------------------------------|--------------------------|
| White British | <input type="checkbox"/> | Mixed white / black Caribbean | <input type="checkbox"/> |
| White Irish | <input type="checkbox"/> | Mixed white / black African | <input type="checkbox"/> |
| White other | <input type="checkbox"/> | Mixed white / Asian | <input type="checkbox"/> |
| Indian | <input type="checkbox"/> | Mixed other | <input type="checkbox"/> |
| Pakistani | <input type="checkbox"/> | Black Caribbean | <input type="checkbox"/> |
| Bangladeshi | <input type="checkbox"/> | Black African | <input type="checkbox"/> |
| Asian other (please specify) | <input type="checkbox"/> | Black other (please specify) | <input type="checkbox"/> |

None of these (please specify)

H4. Are you:

- Male ☐
- Female ☐

H5. What is your religious affiliation?

- None ☐
 - Buddist ☐
 - Christian ☐
 - Jewish ☐
 - Hindu ☐
 - Muslim ☐
 - Sikh ☐
 - None of these (please specify)
-

Section I: Your views on completing the questionnaire

We understand that this questionnaire is about a sensitive topic and we are grateful to you for filling it in. We think it is important to know the views of relatives and friends so that your views can be taken into account when improving services and care. But we want to be sure that we are asking you about your views in the most sensitive way. We would like to learn about your experience of completing this questionnaire.

11. Did you find any aspect of the questionnaire upsetting?

- Yes ☐
- No ☐

If yes, could you tell us more about this?

12. What do you think about the length of the questionnaire? Is it:

- Too long ☐
- Just right ☐
- Too short ☐
- Ok ☐
- Other (please specify)

13. Are there any questions you think we should have left out?

- Yes ☐
- No ☐

If yes, could you tell us more about this?

14. Are there any questions you think we should add?

- Yes ☐
- No ☐

If yes, could you tell us more about this?

**Thank you very much for taking the time to complete
this questionnaire.**

**We would be very grateful if you could return it to us in the stamped
address envelope provided, or post to:**

**Dr Catriona Mayland
Clinical Research Fellow
Directorate of Specialist Palliative Care
1st Floor, Linda McCartney Centre
Royal Liverpool University Hospital
Prescot Street
Liverpool
L7 8XP**

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